

## Economic Burden of Multiple Sclerosis

*Final Report*

HEALTH CARE AND HUMAN SERVICES POLICY, RESEARCH, AND ANALYTICS — WITH REAL-WORLD PERSPECTIVE.



*Prepared for:* **National Multiple Sclerosis Society**

*Submitted by:* **The Lewin Group, Inc.**

*June 9, 2021*



## Acknowledgement

This work was supported by the National Multiple Sclerosis Society. We also thank the technical advisory group who provided invaluable input to this study.

### Lewin Group Project Staff

Grace Yang, MPA, MA  
Inna Cintina, PhD  
Matt Zhou, BS  
Daniel Emont, MPH  
Janice Lin, BS  
Paul Hogan, MS

## Table of Contents

<b>EXECUTIVE SUMMARY .....</b>	<b>6</b>
Methods.....	6
Study Highlights .....	7
Study Findings .....	8
Future Burden Projections.....	12
Discussion .....	12
Conclusion .....	12
<b>I. BACKGROUND .....</b>	<b>14</b>
<b>II. METHODS.....</b>	<b>14</b>
A. Estimating the Direct Medical Cost.....	15
B. Estimating the Indirect and Non-Medical Costs .....	17
<i>Future Earnings Loss due to Premature Death .....</i>	<i>17</i>
<i>Calculation of the Number of Premature Deaths Associated with MS .....</i>	<i>18</i>
<i>Estimation of the NPV of Productivity Losses from premature death.....</i>	<i>20</i>
<i>The Economic Impact of Multiple Sclerosis Survey Study.....</i>	<i>20</i>
<i>Labor Market Employment Related Earnings Loss .....</i>	<i>27</i>
<i>Labor Market Productivity Loss .....</i>	<i>27</i>
<i>Productivity Loss from Forgone Social Activities.....</i>	<i>28</i>
C. Estimating Non-Medical Costs .....	29
D. Estimating the Medical Costs Not Covered by Insurance .....	29
E. Disability Income .....	30
<b>III. RESULTS .....</b>	<b>30</b>
A. Multiple Sclerosis Prevalence.....	30
B. Direct Medical Cost .....	31
C. Indirect Costs.....	33
<i>Premature Death-related Future Earnings Loss .....</i>	<i>33</i>
<i>Labor Market Employment Related Earnings Loss .....</i>	<i>33</i>
<i>Labor Market Productivity Loss .....</i>	<i>34</i>
<i>Productivity Loss from Forgone Social Activities.....</i>	<i>36</i>
D. Non-Medical Costs and Services Not Covered by Insurance.....	38

<i>Non-Medical Costs</i> .....	38
<i>Medical Services Not Covered by Insurance</i> .....	39
<i>Disability Income</i> .....	40
E. Total Economic Burden of MS in 2019 .....	41
<b>IV. PROJECTIONS 2020-2039</b> .....	<b>44</b>
<b>V. DISCUSSION</b> .....	<b>45</b>
Findings and Discussion of the Economic Burden of MS in 2019 .....	45
Comparison with other MS burden estimates and cost of other neurologic diseases in the literature:.....	46
Study Limitations.....	47
Conclusion .....	48
<b>APPENDIX A: COST OF DISEASE-MODIFYING THERAPIES</b> .....	<b>49</b>
<b>APPENDIX B: COMPARISON GROUP CHARACTERISTICS</b> .....	<b>50</b>
<b>APPENDIX C: COMPARISON OF DEATH RATES</b> .....	<b>52</b>
<b>APPENDIX D: SURVEY QUESTIONNAIRE “ECONOMIC IMPACT OF MULTIPLE SCLEROSIS: SURVEY INSTRUMENT”</b> .....	<b>53</b>
Section A: Health Status.....	54
Section B: Family Characteristics .....	58
Section C: Financial Impact of Multiple Sclerosis .....	65
<b>APPENDIX E: SURVEY SAMPLE CHARACTERISTICS</b> .....	<b>77</b>

## Table of Exhibits

Exhibit ES-1. Flow chart of cost calculation and data sources .....	7
Exhibit ES-2. Total economic burden of MS in the U.S. in 2019: \$85.4 Billion .....	8
Exhibit ES-3. Multiple sclerosis prevalence by population characteristics (in 2019) .....	9
Exhibit ES-4. Direct medical cost of MS by age, gender, and insurance coverage (in 2019) ..	10
Exhibit ES-5. The indirect and non-medical costs of MS in the U.S. by cost component (in 2019) .....	11
Exhibit II-1. Estimated number of premature deaths associated with MS (2018).....	19
Exhibit II-2. Sample breakdown by respondents’ self-description from the survey .....	22
Exhibit II-3. Sample breakdown by type of MS .....	23
Exhibit II-4. Disease duration since first symptom and since diagnosis for persons with MS .	24
Exhibit II-5. Percentage of persons with MS who received unpaid care from a caregiver in 2019 .....	24
Exhibit II-6. Baseline characteristics of the persons with MS and unpaid caregivers.....	25
Exhibit II-7. Persons with MS and unpaid caregivers by age and gender .....	26
Exhibit III-1. MS prevalence by population characteristics .....	31
Exhibit III-2. MS disease prevalence by age and gender .....	31
Exhibit III-3. Direct medical cost of MS by age and gender.....	32
Exhibit III-4. Direct medical cost by types of service .....	32
Exhibit III-5. Estimated net present value of the future earnings loss for premature deaths associated with MS.....	33
Exhibit III-6. Estimated labor market earnings loss due to MS related retirement in 2019 .....	34
Exhibit III-7. Percentage of persons with MS and unpaid caregivers employed in 2019 .....	34
Exhibit III-8. Estimated productivity loss due to MS related absenteeism for those younger than 75 (in million \$) .....	35
Exhibit III-9. Estimated productivity loss due to MS disease related presenteeism for those younger than 75 (in million \$).....	36
Exhibit III-10: Percentage of Americans volunteered in the past 12 months and the average number of hours volunteered .....	37
Exhibit III-11. Estimated social productivity loss due to MS .....	38
Exhibit III-12. Estimated formal non-medical care costs due to MS .....	38
Exhibit III-13. Estimated non-medical costs due to MS .....	39
Exhibit III-14. Estimated medical costs due to MS not covered by insurance .....	40
Exhibit III-15. Estimated disability income received by persons with MS in 2019.....	41

Exhibit III-16. The direct medical cost of MS in 2019 by types of services and population characteristics .....	42
Exhibit III-17. The indirect and non-medical costs of MS in 2019 by cost component .....	43
Exhibit III-18. Transfer payments associated with MS to the persons with MS in 2019.....	43
Exhibit IV-1. Projected prevalence and burden 2020-2039 (in 2019 \$) .....	44
Exhibit IV-2. Projected direct, indirect, and non-medical costs 2020-2039 (in 2019 \$) .....	45
Exhibit A-1. Percent of people with MS treated with DMT and per capita DMT cost (in 2019) .....	49
Exhibit B-1. Comparison of age, gender, & race/ethnicity between MS and comparison groups by data source .....	50
Exhibit B-2. Comparison of per-capita cost between MS and comparison groups, by age, gender, and insurance (in 2019 \$) .....	51
Exhibit C-1. Comparison of death rates derived from CDC Wonder and Medicare 5% data for the MS and non-MS's elderly population (2018).....	52
Exhibit E-1. Education attainment and marital status of the persons with MS and unpaid caregivers.....	77
Exhibit E-2. Total individual earnings in 2019.....	78
Exhibit E-3. Symptom severity for persons with MS.....	79
Exhibit E-4. Health conditions among persons with MS .....	80

## Executive Summary

As of 2017, nearly 1 million adults (up to 913,925) were living with Multiple Sclerosis (MS) in the U.S.<sup>1</sup> MS disease onset usually occurs between ages 20 and 40 years, leading to gradual physical decline. 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> Individuals with MS experience higher rates of comorbid health conditions such as hypertension, high cholesterol, major depression, and type II diabetes which impacts overall neurological morbidity.<sup>3</sup>

MS is associated with a multitude of symptoms<sup>4</sup> and they may intensify and subside over time, creating a relapsing-remitting pattern. While MS and progressive MS are rarely the direct cause of death, its debilitating effects on normal body function result in considerable disruption to daily living and life roles including work, physical independence, mobility, social interaction, and participation in recreational activities.<sup>5</sup> As a result, individuals with MS have higher medical needs, often miss work, retire early, and require the assistance of a caregiver.<sup>6</sup> As such, the direct and indirect economic burden of MS is likely to be significant for the patient, the unpaid family caregivers, and from the societal perspective.

As part of its initiative to understand the economic burden of MS, the National Multiple Sclerosis Society (NMSS) commissioned the Lewin Group to estimate the economic impact of MS in the U.S. in 2019. This study aims to provide the most comprehensive assessment of the total burden of MS to date, including filling the knowledge gap in some of the less well-understood cost components, such as future earnings loss due to premature death, productivity loss in both the labor market and in social life, and caregiver burden.

## Methods

We took a prevalence-based approach in estimating the burden of MS in 2019, where the prevalence of MS is combined with per-capita cost to derive the national economic burden, broken down by population characteristics. Multiple data sources were used to estimate the cost components of MS (**Exhibit ES-1**). We relied on MS prevalence estimates for year 2010 that are published in Wallin et al (2019).<sup>1</sup> To obtain the 2019 MS estimates, we used the strategy described in Wallin et al (2019) and applied an annual growth rate of 2.3% to the 2010 estimates. We used the Medicare Current Beneficiary Survey (MCBS) data, claims data from the Medicare Standard Analytical File (Medicare SAF 5%), and Optum de-identified Normative Health Information (dNHI) System data (a large claims database for the privately insured), to estimate the direct medical cost of MS.<sup>7,8,9</sup> Direct costs were calculated as the difference in the per-person average annual paid amount between persons with MS and matched controls without MS (based on age, gender, race/ethnicity, and insurance). Future earnings loss due to premature deaths attributable to MS was estimated using CDC WONDER data and the Medicare analytical files, among others. Additionally, we designed and implemented a primary survey to estimate other indirect and non-medical cost components, including:

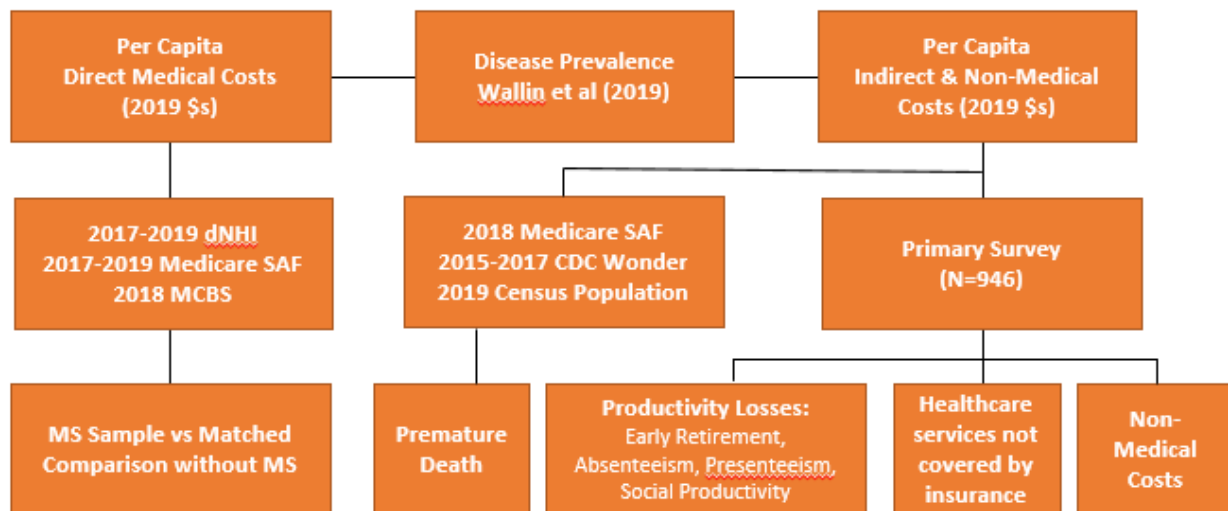
1. Loss in labor market earnings for persons with MS and their unpaid caregivers due to early retirement;



2. Productivity loss and reduced labor market productivity, including absenteeism and presenteeism, for persons with MS and their unpaid caregivers;
3. Productivity loss from reduced participation in social activities for persons with MS and their unpaid caregivers;<sup>10</sup>
4. Non-medical costs of MS such as the cost of hiring professional non-medical caregivers to assist with daily living, necessary home modification costs, and increased transportation costs.

The primary survey was also instrumental in collecting data on medical direct costs for treatments that are not covered by insurance and, hence, are paid out-of-pocket by people with MS. Such expenses include experimental treatments like Hematopoietic Stem Cell therapy (HSCT) related to MS, alternative and non-traditional treatments, and expenses on medical cannabis for MS-related symptoms. The survey also captured transfer costs in government provided supplemental disability income (e.g., Supplemental Security Income [SSI] and Social Security Disability Insurance [SSDI]) that although are presented in this report, however excluded from the overall burden estimate.

**Exhibit ES-1. Flow chart of cost calculation and data sources**



Abbreviations: dNHI: Optum de-identified Normative Health Information system; Medicare SAF: Medicare Standard Analytical File 5% sample; MCBS: Medicare Current Beneficiary Survey; CDC: Centers for Disease Control and Prevention.

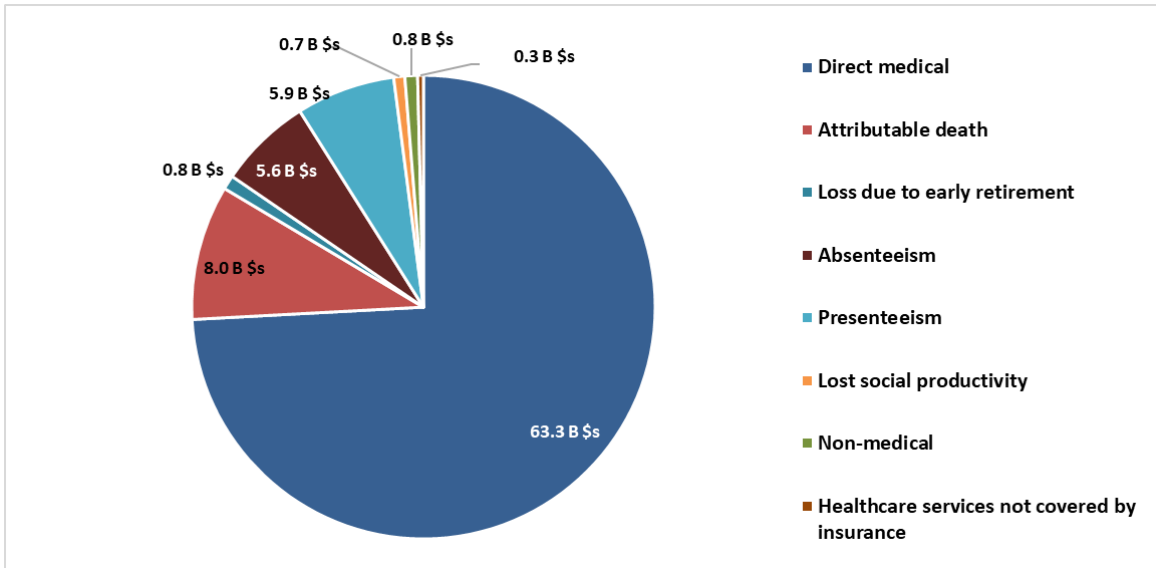
### Study Highlights

This study provides the most comprehensive assessment of the economic burden of MS in the U.S. in 2019. The estimated total economic burden of MS in 2019 was \$85.4 billion, including a direct medical cost of \$63.3 billion and an additional nearly \$21.0 billion in indirect cost and \$1.1 billion in non-medical costs and cost of healthcare services not covered by insurance. These findings show that the impact of MS has been previously underestimated in the literature.

**Exhibit ES-2** shows the estimated total economic burden of MS in the U.S. in 2019 by cost components.



**Exhibit ES-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 claims, 2017-2019 Medicare Standard Analytical File 5% sample claims, and 2018 Medicare Current Beneficiary Survey (MCBS); indirect and non-medical cost estimates are from the MS Impact Survey.

Another highlight of the study is the Economic Impact of Multiple Sclerosis Survey (i.e., the MS Impact Survey). This primary survey was specifically designed and administered for this study to deepen the understanding of the full spectrum of MS impact. Via this survey, we were able to collect detailed data on a broad set of indirect and non-medical costs of MS that were previously unavailable, especially the impact of MS on unpaid caregivers.

**Study Findings**

MS prevalence in 2019 was estimated relying on the estimates previously reported in the literature. **Exhibit ES-3** shows the estimated MS prevalence:

- About 1.00 million individuals in the U.S. are estimated to have MS in 2019.
- The largest strata of individuals with MS is the older population 45-74; prevalence among younger population (18-44) is similar to those older than 75 and is less than half of prevalence among population 45-74.
- More females than males have MS.

### Exhibit ES-3. Multiple sclerosis prevalence by population characteristics (in 2019)

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

Source: Wallin et al (2019). We applied the 2.3% annual growth factor to the 2010 estimates to calculate prevalence in 2019.

The overall economic burden of MS is \$85.4 billion, of which 74% are direct medical costs (\$63.3 billion) and 26% are indirect costs and non-medical costs (\$22.1 billion, of which \$21.0 billion are indirect costs associated with productivity losses and \$1.1 billion are non-medical costs and healthcare costs not covered by insurance).

MS is associated with a significant amount of excess medical cost: \$63.3 billion in 2019, higher than the previous U.S. based estimates. **Exhibit ES-4** shows the estimated excess direct medical cost of MS.

- On average, the excess per person annual medical cost of MS is \$65,612 above that of individuals who do not have MS.
- The vast majority of the medical cost of MS is borne by the largest group of people with MS - population aged 45-64 (52%) with per person excess medical costs of \$67,230; the Medicare population represents the smallest share (22%) and also has smaller per person costs – \$63,175.
- Excess medical costs for females with MS are \$45.9 billion and represent about 72% of the total direct medical costs; however, the per-person excess costs for females are smaller than those for males with MS (\$63,896 vs \$70,603).
- Beside the prescription medication related costs that include cost of DMT, outpatient medication and administration and other outpatient care (including outpatient facilities and other ancillary care) are the largest cost categories. Per person cost of outpatient medication and administration is \$8,049 and \$5,737 for other outpatient care.
- Usage of DMT varies substantially by age group and not all MS patients are treated with DMT. **Exhibit A-1** in Appendix A shows that about 50% of adults age 18-64 with MS are treated with DMT. Usage is lower among the Medicare age population: 40% of females and about 20% of males are treated with DMT. Cost per user of DMT ranges from

\$57,202 to \$92,719 depending on gender-age strata, with the highest per DMT-user estimate being for males over 65 years old. Cost of prescription medication for the Medicare population is from the MCBS data due to lack of prescription drug claims in the Medicare 5% claims. One of the shortcomings of the MCBS data is the small sample size; hence, the DMT cost estimates for those over 65 years old might be inaccurate and subject to fluctuations.

**Exhibit ES-4. Direct medical cost of MS by age, gender, and insurance coverage (in 2019)**

	Total Excess Medical Cost due to MS		Per person (\$)
	(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 combined with direct medical cost estimates using 2017-2019 dNHI claims, 2017-2019 Medicare SAF 5% sample claims, and the 2018 Medicare Current Beneficiary Survey (MCBS). DMT: disease-modifying therapies.

- The estimated total indirect and non-medical cost of MS is nearly \$22.1 billion in 2019, with nearly \$18.0 billion to persons with MS and another \$4.2 billion to unpaid caregivers. **Exhibit ES-5** shows the estimated indirect and non-medical cost of MS:
- Average indirect and non-medical cost per capita is \$18,542 for persons with MS only and \$22,875 for persons with MS combined with caregiver burden.
- Total combined indirect cost for persons with MS and caregivers is \$21.0 billion, with premature death related earnings loss being the largest share (36%), followed by productivity losses due to presenteeism (27%) and absenteeism (25%). The cost of absenteeism and presenteeism for the caregivers are about half of those for the persons with MS.

- Total non-medical cost is \$0.7 billion with the paid non-medical daily care being the largest share (33%).
- Non-traditional healthcare services that are not covered by insurance (e.g., experimental, alternative, and non-traditional treatments, medical cannabis for MS-related symptoms) represent \$0.3 billion.

**Exhibit ES-5. The indirect and non-medical costs of MS in the U.S. by cost component (in 2019)**

	Total Indirect and Medical Costs (in Million \$s)			Per Person (\$)		
	Person with MS Loss	Caregiver Loss	Person with MS & Caregiver	Person with MS Loss	Caregiver r Loss	Person with MS & Caregiver
<b>Indirect Costs</b>	<b>\$16,801</b>	<b>\$4,182</b>	<b>\$20,984</b>	<b>\$17,407</b>	<b>\$4,333</b>	<b>\$21,741</b>
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
<b>Non-Medical Costs</b>	<b>\$752</b>	<b>NA</b>	<b>\$752</b>	<b>\$780</b>	<b>NA</b>	<b>\$780</b>
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
<b>Healthcare services not covered by insurance</b>	<b>\$342</b>	<b>NA</b>	<b>\$342</b>	<b>\$355</b>	<b>NA</b>	<b>\$355</b>
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, Bureau of Labor Statistics earnings data; prevalence estimates are from Wallin et al (2019) and Census population projection for 2019.

Additional \$6.7 billion were transfer payments due to disability income or other financial assistance received by the persons with MS. SSDI is the largest share in the disability income cost component (60%). We did not include transfer payments into the overall burden estimates, as transfer payments constitute redistribution of resources from one group to another (hence, benefit for recipients, cost for the payer). Additionally, SSI and SSDI payments might be used by families to pay out-of-pocket (OOP) costs or caregiver costs; in this case, one will be double counting this resource twice, given that we reported OOP costs and costs associated with hiring paid care and

other non-medical costs. However, this component may inform one on the extent of government budgetary burden due to MS and, hence, reported here as well.

## Future Burden Projections

Our projections show that the prevalence of MS in the U.S. will conservatively increase to 1.2 million people by 2039. This projection takes into account changes in population demographics but assumes that annual changes in prevalence rates by gender-age group strata will remain constant at 2.3% over the projection horizon. The economic burden of MS is projected to increase to \$108.1 billion in 2039 from \$85.3 billion in 2019. This projection relies on applying the 2019 per person burden estimates to the projected prevalence.

## Discussion

Per person direct medical cost and indirect and non-medical costs estimated in this study are higher than in the previous U.S. based MS burden studies.<sup>11,12</sup> For example, Whetten-Goldstein et al (1998) estimated the total annual cost of MS in 1994 to be over \$34,000 per person (\$58,652 in 2019 dollars).<sup>11</sup> This estimate excludes cost of DMT, which were introduced in later years.<sup>13</sup> A more recent study by Kobelt et al (2006) estimated that the total average cost of MS in 2004 was about \$47,215 per-patient per-year (\$59,875 in 2019 dollars).<sup>12</sup> However, direct costs in this study are estimated from the survey responses and represent the total rather than excess costs and, hence, are not comparable. Previous studies have significantly different data sources, methods, and included different cost components of interest. Therefore, any comparison between the findings of this new study and any previous literature should consider these differences.

## Conclusion

This new study provides a comprehensive evaluation of the current and future impact of MS in the U.S. Using diverse and best available primary and secondary data sources, we estimated the overall economic burden of MS to be \$85.4 billion in 2019, including \$63.3 in direct medical cost and nearly \$22.1 billion in indirect cost, non-medical costs, and healthcare costs for treatments not covered by insurance. This estimate is much higher than previously understood due to both a higher prevalence estimate and high per-capita cost (per-capita direct medical cost is \$65,612 and indirect, non-medical cost, and medical care not covered by insurance is \$22,875 when persons with MS and care partner losses are combined). Our findings show that MS significantly affects persons with MS, their unpaid caregivers, as well as payers and employers. The commercial insurers bear the largest share of excess medical cost, as most persons with MS are below the age of 65. Employers experience significant productivity loss from those individuals with MS who are in the labor force, but either miss workdays due to MS or have reduced productivity on some days due to MS. The government transfer payments providing disability income to persons with MS and their caregivers who lose the ability to participate in labor market or volunteer activities are also large. While transfer payments represent about half of the productivity losses to employers, we did not include them in the total burden estimate due to their nature.

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 suggest 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 the decision-making regarding MS related health resource investment and prioritization.

## I. Background

A recent study estimated that as of 2017, nearly 1 million adults (up to 913,925) were living with multiple sclerosis (MS) in the U.S.<sup>1</sup> MS disease onset usually occurs between ages 20 and 40 years, generally leading to gradual physical decline. 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> Individuals with MS experience higher rates of comorbid health conditions such as hypertension, high cholesterol, major depression and type II diabetes than the general population.<sup>3</sup>

MS is associated with a multitude of symptoms<sup>4</sup> and they may intensify and subside over time, creating a relapsing-remitting and progressive patterns. While MS is rarely the direct cause of death, its debilitating effects on normal body function can result in considerable disruption to daily living and life roles including work, physical independence, mobility, social interaction, and participation in recreational activities. Individuals can require considerable assistance with activities of daily living (e.g., dressing, bathing).<sup>5</sup> It is the leading progressive neurological condition of young working-age adults with nearly 30 percent of working-age individuals across the U.S. who reported having MS currently reliant on Social Security Disability Insurance (SSDI).<sup>14</sup> Family caregivers are the primary providers of daily care for loved ones living at home.

Meta-analyses have shown that MS ranked second behind congestive heart failure in direct all-cause medical costs for chronic conditions.<sup>15</sup> In addition, as patients with MS age and their disabilities progress, the healthcare costs of managing the disease can also increase due to the greater likelihood of needing costly healthcare services (e.g., emergency room [ER] visits, long-term care).

The previous studies examining economic burden of MS in the U.S. are outdated due to recent changes in the prevalence estimates of MS in the U.S. and the development of new treatment techniques and pharmacotherapies in the last two decades. Thus, there is a need for a comprehensive reassessment of the economic impact of MS in the U.S. The objective of this study was to conduct up-to-date estimations of the economic burden of MS in the U.S and address a number of the limitations in the existing literature. Using more up-to-date and more relevant data sources, we estimated the direct, indirect, and non-medical costs associated with MS for the calendar year 2019. We also implemented a primary survey, designed to enrich the economic burden estimates by providing more detailed insight on a broader set of indirect and non-medical costs specific to the MS community. This survey enabled us to estimate the caregiver burden and utilize more comprehensive measures of labor market consequences for the Person with MS and their caregiver than what is available from secondary data sources. The survey also allowed us to estimate costs associated with adjustments to the disease, such as renovations to homes and motor vehicle modifications, and spending on professional caregivers. This information is critical for policy relevant decisions that can lead to effective allocation of healthcare resources and prioritizing treatment services and coverage policies for those living with MS.

## II. Methods

Due to a lack of a uniform data source and approaches to estimating the total burden of MS, we relied on a variety of primary and secondary data sources to estimate different components of the



cost of MS, including existing national survey data, public and private claims data, national death records, and a primary survey specifically designed for this study. The disease attributable cost approach was used to estimate the direct cost of MS, and a human capital approach was used to calculate the indirect cost of MS. To obtain clinical guidance and ensure study validity, a technical advisory group (TAG) was formed to shepherd the study from beginning to completion. The TAG was comprised of several nationally renowned clinical and health policy experts who helped provide relevant early input, engage in discussions, and review interim and final deliverables, including the review of the survey instrument. Below, we describe the analytical method for each study component, in their respective sections.

## **A. Estimating the Direct Medical Cost**

Persons with MS often experience a range of additional complications and comorbidities. MS may also complicate the treatment of conditions unrelated to MS. Therefore, in calculating the medical cost of MS, it is important to capture health resource use for both the direct treatment of MS itself and the proportion of the cost of treating other conditions related to MS. To quantify the overall excess healthcare use due to MS, we compared the healthcare costs of Persons with MS with that of a matched comparison group with similar characteristics but without MS. The difference between the average costs of the comparison group and the study group was used to estimate the excess medical cost due to MS.

Three key data sources were used for this analysis:

- For the privately insured population (<65 years of age), we used the proprietary Optum de-identified Normative Health Information (dNHI) system, a longitudinally-linked and statistically de-identified claims database. This research database contains a comprehensive set of medical, prescription drug, and laboratory claims, membership information (including member demographics), provider, and ancillary data for approximately 130 million cumulatively covered lives since 2000. Any services covered by the private health plans, including long-term care such as skilled nursing facility (SNF) or nursing home care are also included. We used the 2017-2019 data (with a total membership of more than 30 million privately insured individuals) for this analysis.
- For the Medicare eligible population (including those age 65 and older and those <65 who were eligible for Medicare due to disability), we used the Medicare Standard Analytical File 5% sample claims data in years 2017-2019. The Medicare 5% data includes both institutional (inpatient, outpatient, skilled nursing facility, hospice, and home health agency) and non-institutional (physician and durable medical equipment providers) claim types. One limitation of the Medicare 5% data is that it does not include Part D prescription drug claims, nor does it include any benefits not covered by Medicare, such as long-stay SNF claims or nursing home care.
- Due to the fact that the Medicare 5% does not include prescription drug and long-term care claims, we used the 2018 MCBS to estimate the cost of these two components for the Medicare eligible population. The MCBS aims to provide a complete picture of the expenditure and source of payment data on all healthcare services received by the entire Medicare population. It links beneficiary characteristics with the claims of the Medicare fee-for-service (FFS) population and includes survey-reported healthcare events including prescription medicine events and costs for those covered by Medicare Advantage (MA)

plans or the prescription drug plans (PDP). MCBS also collects data on healthcare services received by the Medicare population that are not covered by Medicare, such as long-term care cost, for both FFS and non-FFS members, as well as for the Medicare beneficiaries dually covered by other health plans, such as Medicaid. The costs from this data source were inflated to 2019 dollars.

In the dNHI and the Medicare SAF files, we first identified the study group – persons with MS – using an algorithm consistent with what was used in the recent MS prevalence study:<sup>1</sup>

**Step 1.** Identify beneficiaries who have continuous coverage for both medical and pharmacy benefits in the study year;

**Step 2.** Flag a beneficiary as having MS, if the beneficiary has:

- MS diagnosis code (ICD-9/ICD-10): ICD-9 code 340 or ICD-10 code G35 at any time during the year 2019 at either the primary or the secondary diagnosis positions; AND
  - For dNHI claims: Requiring  $\geq 3$  MS-related inpatient, outpatient visits, or prescription claims for an MS disease-modifying therapy (DMT) in any combination within a 1-year period;
  - Due to the limitation that Medicare 5% SAF does not include Part D drug claims, for Medicare 5% claims: Requiring  $\geq 2$  MS-related inpatient or outpatient visits in any combination within a 1-year period;

For the 2018 MCBS file: Requiring  $\geq 2$  MS-related medical claims, any drug claim for a DMT, or in the MCBS survey file one answers that he/she has MS.

Next, for each person with MS included in the study group by insurance coverage, people without any evidence of MS were matched based on age, gender, and race/ethnicity, and insurance. A 10:1 ratio was used to identify the comparison groups. Because MS is likely to affect the whole health, we did not want to over-control. We did not account for other factors in matching, as age, gender, race/ethnicity and insurance already control for conditions that are unlikely to be correlated with MS (e.g. flu, if we assume that people of same age/sex/race/insurance have the similar likelihood of getting flu). A comparison of the study and comparison group characteristics are shown in **Exhibit B-1** in Appendix B. For each group, we calculated the per person direct medical costs; the difference between the two per person costs represents the excess per person costs associated with MS.

Direct medical cost of MS included the amount paid to providers by health insurance, the person's out-of-pocket expenses (e.g. copayments, coinsurance, and deductibles), and other third party paid amount (e.g., any payments made to the provider by a spouse's insurance). The excess medical costs were calculated for 2017, 2018, and 2019; then we calculated a 3-year average to smooth possibility that one particular year is an outlier.

We estimated the direct medical cost of MS by insurance, age, gender, race/ethnicity, and types of healthcare services, including cost of hospital inpatient stay, physician office visit, prescription medications, administration of prescription medication, durable medical equipment, outpatient services (e.g., hospital outpatient care, physical therapy, occupational therapy, and all other ancillary services), and non-acute institutional care (including SNF, nursing home, hospice, and

other similar services). Prescription medication cost includes DMT costs identified based on the National Drug Code (NDC) list. These do not include the cost of DMT infusion procedures. However, administration of medication in the outpatient setting is captured by the outpatient medication and administration category, which was identified from outpatient/physician claims data based on Current Procedural Terminology codes 96401-96549, or less complex IV codes 96360-96379, or HCPCS codes starting with letter "J" for injectable drug including injectable DMT.

## **B. Estimating the Indirect and Non-Medical Costs**

The indirect and non-medical cost of MS is multifaceted and is anticipated to have significant impact on persons with MS, their caregivers, and families. However, information on these cost components is sparse in the literature. This study aimed to fill the gap in evidence from the existing literature by addressing five areas of indirect or non-medical cost components of MS, including:

1. Future earnings loss due to premature death
2. Loss in labor market earnings for persons with MS and their unpaid caregivers due to early retirement
3. Productivity loss due to reduced labor market productivity, including absenteeism and presenteeism for persons with MS and their unpaid caregivers
4. Productivity loss from reduced participation in social activities for persons with MS and their unpaid caregivers, and
5. Non-medical costs of MS such as the cost of hiring professional non-medical caregivers to assist with daily living, necessary home modification costs, and increased transportation costs, etc.

Among these five cost components, item 1 – future earnings loss due to premature death – was estimated using secondary data sources, especially the Centers for Disease Control and Prevention (CDC) Wide-ranging OnLine Data for Epidemiologic Research (WONDER) Detailed Mortality Database<sup>16</sup>, Medicare 5% sample claims data, and Bureau of Labor Statistics (BLS) earnings data<sup>17</sup>. Items 2-5 were estimated using data from a primary survey specifically designed for this study – the Economic Impact of Multiple Sclerosis Survey. Additionally, our survey covered expenditures for medical treatments that are not covered by insurance such as experimental, alternative and non-traditional treatments for MS, as well as data transfer costs in government provided supplemental disability income such as SSI and SSDI. The latter are presented in this report, however they are excluded from the overall burden estimate.

Below, we first describe our methods for estimating the premature death related cost, and then describe the survey development, the survey completion rates, sample characteristics, and how we used the survey questions to calculate the cost estimates for items 2-5 above, as well as out-of-pocket expenditures for treatments not covered by insurance.

### ***Future Earnings Loss due to Premature Death***

Although MS can be a cause of or contributor to mortality, the cause of death of persons with MS is often listed as one or more other factors, such as hypertension, hyperlipidemia, and chronic lung disease, among others.<sup>18</sup> Drawing on data from the CDC WONDER mortality database (see details below), Medicare 5% Sample claims data, and existing vital statistics, labor force participation,

and earnings data, we estimated the total net present value (NPV) of future earnings loss due to premature death associated with MS.

To calculate loss in earnings, we first estimated the number of premature deaths associated with MS and then multiplied that number by an estimate of the present value of future earnings. We computed the NPV of future earnings for men and women by age group (i.e., 18-44, 45-64, 65-74) to estimate the national productivity loss of early mortality associated with MS. The approach incorporates information on average annual earnings, takes into account labor force participation rates and mortality rates for men and women in the U.S., and assumes a productivity growth rate of 1% and a discount rate of 3%, a rate often used in public health studies.<sup>19,20,21</sup> Because labor force participation rates and average annual earnings are low for the elderly aged 75 years and older and the expected life expectancy falls within this age group, we limited our calculation of earnings loss to adults 18-74 years of age (i.e., loss in earnings is assumed to be 0 for individuals who die prematurely due to MS at age 75 and above).

### ***Calculation of the Number of Premature Deaths Associated with MS***

To calculate the number of premature deaths associated with MS, we first calculated and compared death rates for the MS and non-MS population. We then multiplied the size of the MS population by the difference in death rates to estimate the number of extra (i.e., premature) deaths associated with MS.

Two sources of data were used to calculate the death rates for the MS and non-MS populations: 2015-2017 CDC WONDER multiple cause of death data (publicly available on CDC's website) and Medicare 5% claims data. The CDC WONDER data are the main source of death data in the U.S. and are based on death certificates for U.S. residents. Deaths associated with MS were identified based on the presence of at least one diagnosis code for MS as the underlying cause of death or as one of the multiple causes. All other deaths were attributed to the non-MS population. Deaths were estimated for 2018 based on annual trends in the number of deaths between 2015 and 2017.

In the Medicare 5% claims data, we focused our analysis on beneficiaries with at least one month of Part A and B coverage during 2018 and who were identified as having MS during their Medicare enrollment. Deaths were identified based on the presence of a death date.

Both data sources were used to calculate the death rates for the MS and non-MS populations because neither data source provided reliable death rates for both the MS and non-MS populations and for all ages. While the CDC WONDER data is the national data source for deaths, it is not an ideal source of deaths associated with MS. Death certificates underreport deaths attributed to the disease because MS is often a secondary cause of death and the causes of death of persons with MS are often listed as other factors. While the Medicare population is representative of the U.S. elderly population in general, that is not the case for non-elderly adults, who are only eligible for Medicare under certain circumstance (e.g., disability, end-stage renal disease).

For these reasons, we used the 2018 Medicare 5% data to calculate the death rates for both the elderly MS and non-MS populations and the WONDER data for calculating the death rate for the non-elderly population without MS. See **Exhibit C-1** in Appendix C for a comparison of death rates derived from CDC WONDER and Medicare 5% data for the Multiple Sclerosis disease and

Non-Multiple Sclerosis' elderly population. It is notable that the death rate calculated based on death certificates that mention MS as a cause of death (CDC WONDER) is actually lower than that in the general population. Therefore, relying on this data would lead to underestimation of deaths among the elderly population with MS. That is why for the elderly MS population, we relied on death rates derived from the Medicare 5% data.

For individuals younger than 65 years of age with MS, we estimated the 2018 death rates based on both data sources:

- Using the Medicare 5%, we first identified the MS/non-MS death ratio for individuals aged 65, 66, 67, through 74, and estimated the annual change in the death ratio between age 65 and 74 using regression analysis (-0.08 for males, -0.20 for females).
- Using the WONDER data, we calculated a death rate for the non-MS population for each age 18-64.
- We calculated the MS/non-MS death ratio for each age 18-64 by applying the relationship derived from regression analysis for those 65-74.
- We then multiplied the WONDER non-MS death rate for each age 18-64 by the calculated death ratio for the age to derive an estimated MS death rate for each age.

Using the derived death rates, we calculated the difference in death rates for the MS and non-MS populations for each age and then multiplied the difference by the size of the MS population for that age to calculate the number of premature deaths associated with MS. **Exhibit II-1** below presents the final death rates for both the MS and non-MS populations and the estimated premature deaths associated with MS by gender and age group.

**Exhibit II-1. Estimated number of premature deaths associated with MS (2018)**

	MS Death Rate	Non-MS Death Rate	Difference in Rates (MS - non-MS)	Estimated Number of Premature Deaths for MS
<b>Males</b>				
18-44 years	1.24%	0.19%	1.05%	689
45-64 years	3.22%	0.81%	2.41%	3,049
65-74 years	6.92%	2.30%	4.62%	2,030
<b>Females</b>				
18-44 years	1.25%	0.09%	1.16%	2,071
45-64 years	3.14%	0.49%	2.65%	10,004
65-74 years	5.82%	1.49%	4.33%	5,888

Source: Lewin analyses of 2015-2017 CDC Wonder and 2018 Medicare 5% sample claims data. Death rates for ≥65 years were derived from Medicare 5% data. Death rates for <65 non-MS population were derived from CDC WONDER data. Death rates for <65 year-old MS population are estimated.



## ***Estimation of the NPV of Productivity Losses from premature death***

Overall, NPV of future earnings was calculated in two main steps:

1. We first calculated the present value (PV) of future earnings for each year following death 18-74 (by gender), adjusting for survival and employment rates, productivity growth (1%), and a discount factor (3%). 2018 earnings and employment rates for the U.S. population by gender and age group were obtained from the BLS (we applied an inflation factor to express them in 2019 \$);<sup>22</sup> survival rates were sourced from the CDC National Vital Statistics Report.<sup>23</sup> The estimated PV of future earnings were then summed across each year to determine the total earnings loss based on each possible year of death (e.g., for someone who died at 72, we totaled the PV of future earnings for age 72, 73 and 74).
2. We then determined the average NPV of future earnings for all ages in an age group based on the size of the MS population within an age group.

Once the average NPV of future earnings for each age group was determined, we multiplied this value by the number of premature deaths within each age group to derive the estimated earnings loss from premature death due to MS.

The calculation of earnings loss is based on information about annual earnings and adjusts for employment rate and mortality risk by age and gender. It is important to highlight that all of these inputs were based on publicly available statistics for the general U.S. population. We were not able to incorporate MS-specific information on earnings and employment due to a lack of data. Specifically, in the MS Impact Survey, we asked about earnings and employment for people with MS in 2019. However, we did not collect data about their earnings prior to 2019 or prior retirement decision. Therefore, we did not use these data in calculating future earnings' loss, because survey respondents may have already reduced the probability of employment and earnings' power, so relying on these data would underestimate the true economic impact of premature death among MS patients, should they remain healthy, productive labor market contributors. In addition, these inputs were not available for specific ages but instead age groups. Therefore, the same earnings and employment rate assumptions were used for all ages within a given age group.

## ***The Economic Impact of Multiple Sclerosis Survey Study***

We designed a primary survey – the Economic Impact of Multiple Sclerosis Survey (will hereafter be referred to as the MS Impact Survey), to collect data to estimate the indirect cost of MS due to reduced labor market participation, productivity loss for those in the labor force and not in the labor force, cost of providing disability supplemental income, and the key items of non-medical costs of MS, such as the cost of hiring professional non-medical caregivers to assist with daily living, home modification costs and increased transportation costs, etc. A key purpose of the survey was to help understand the extent of family caregiver burden, which is a critical component of the indirect cost burden of MS.

### ***Survey Design and Sampling***

The survey included 32 questions on several key domains, including: 1) health status, disease history, and severity of MS; 2) demographic, socio-economic characteristics, and insurance coverage of the person with MS; 3) informal caregiver profile and caregiver roles and responsibilities; 4) employment status, productivity, and annual earnings of the person with MS

and caregivers; and 5) non-medical costs. The majority of the questions were close-ended and written at an appropriate literacy level (approximately 8<sup>th</sup> grade reading level). Given that respondents may be in poor health, we minimized the use of skip patterns, which might have been confusing for some respondents. Additionally, we allowed the family member most familiar with the person with MS's health to respond to the survey on behalf of the person with MS, if the person with MS's health would prevent accurate self-report.

The key questions of the survey were created to be as similar as possible to the existing validated questions in some of the nationally representative health surveys (e.g., the Medical Expenditure Panel Survey, the National Health Interview Survey, the Health and Retirement Study, etc.). Lewin also conducted an environmental scan based on the information needed to augment questions on person of MS and caregiver social wellbeing and financial status. The survey went through several rounds of reviews and critique including that of the TAG, as related to the validity, readability, and comprehensiveness of the questions.

A pilot version of the survey was created to assess the difficulty scale of answering the key questions and how each question can be improved. This draft version was sent to 35 NMSS members. A total of 22 responses were received with 11 of them completing the entire questionnaire and 11 providing incomplete responses. Based on the feedback received from the 11 complete responses and the patterns of attrition from the incomplete responses, we optimized the survey questions, changed the order of questions, adjusted the skip logic of questions, and clarified or reduced the difficulty levels of certain questions. The final survey was programmed into Qualtrics - an online survey platform. Survey questionnaire is included in Appendix D.

Using the hypothetical income loss as a key outcome variable, we conducted a power analysis that found that when assuming a one-sample mean income loss of \$10,000 and a standard deviation of \$20,000, a sample size of approximately 126 would be needed at the 0.05 significance level and 80% power in order to detect a difference from a "population" mean of an income loss of  $\pm$ \$5,000. Assuming a response rate of 25%, we would need to target a sample of at least 504 potential respondents for one strata of interest. With the key individual characteristics of interest being age (4 groups) and gender (2 groups), we would need to survey across 8 strata, targeting a total number of a little more than 4,000 individuals with MS, with an anticipated final sample size of around 1,000.

Despite the intention to use a stratified random sampling approach, an examination of the possible sources for a sampling frame indicated that obtaining the contact information of the entire U.S. MS population was infeasible. Therefore, we took a convenience sample approach and distributed the survey to the individuals in the NMSS contact list who were listed as having MS.

### *Survey Implementation*

The survey was administered electronically via the online survey vendor – Qualtrics. Qualtrics platforms have functions to record non-response, item non-response, and partial survey completions and restrictions were placed to allow each respondent to answer the survey only once. Link to the online survey was then sent to individuals in the NMSS contact list via e-mail distribution.



The survey was launched among the target populations following email introductions of the incoming survey, including its importance to the MS community and the logistics of responding to the survey. The survey was open for 4 weeks and up to two rounds of follow-up reminders to non-respondents were sent before the established closing date.

The survey did not include any personally identifiable information and was approved by the New England Institutional Review Board. Final datasets were accessible to Lewin in a strictly de-identified format to ensure person with MS and family confidentiality and privacy.

### Survey Completion Rate

A total of 1,766 households responded to the survey. Among them, 949 (53.7%) completed the survey according to the electronic recording. The breakdown of survey respondents, based on how they describe themselves, shows that there were 3 respondents who answered that they do not have MS or don't know anyone with MS. Eliminating these 3 responses from the analytic file resulted in the final sample of 946 observations. Among the 946 respondents included in the final sample, 4 respondents (0.4%) indicated that the person with MS in their family had passed away. Since the number of respondents who had passed away was small, taking into account the year when they passed away and per consultation with the NMSS, we decided to exclude these four observations from the final sample. (**Exhibit II-2**).

**Exhibit II-2. Sample breakdown by respondents' self-description from the survey**

Which of the following <u>best describes you</u> (the person who is responding to the survey)?	Freq.	Percent
A person with MS	869	91.6
A family caregiver for someone who has MS	58	6.1
A paid caregiver for someone who has MS	1	0.1
A family member of someone who has MS, but not a direct caregiver (e.g., family member who is not responsible for organizing/providing day-to-day care)	18	1.9
A close friend to someone who has MS, but not a caregiver	0	0
<b>Sub-total</b>	<b>946</b>	
Do not have MS, no one in the family had MS, and do not know anyone with MS	3	0.3
<b>Total number of respondents</b>	<b>949</b>	<b>100</b>

Source: Primary data collected through the MS Impact Survey.

**Exhibit II-3** shows the breakdown of survey respondents by type of MS. Nearly 70% of respondents had relapsing-remitting MS; secondary-progressive MS was the second most common type of MS among the survey's respondents (16.9%).

**Exhibit II-3. Sample breakdown by type of MS**

	Unweighted		Weighted	
	Frequency	Percent	Frequency	Percent
<b>Total</b>	<b>946</b>	<b>100.0</b>	<b>965,184</b>	<b>100.0</b>
Relapsing-Remitting MS (RRMS)	676	71.5	667,366	69.1
Primary-Progressive MS (PPMS)	93	9.8	100,806	10.4
Secondary-Progressive MS (SPMS)	146	15.4	163,108	16.9
Clinically Isolated Syndrome (CIS)	6	0.6	7,225	0.7
Other	8	0.8	9,043	0.9
Do not know	17	1.8	17,636	1.8

Source: Primary data collected through the MS Impact Survey.

Despite our concerted efforts to recruit a more representative sample for the survey, it may be the case that the survey sample is skewed in certain dimensions. 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 identified using prevalence estimates from Wallin et al (2019) (see **Exhibit II-6**) and have slightly more females. Therefore, we stratified the survey sample and the MS population both into age group and gender strata and created weights for each survey respondent to represent the underlying population, given the population distribution in age and gender. The weight variable was calculated as the reciprocal of the probability of each survey sample person being selected out of the total population that has the same characteristics. Final weights were used in all analyses describing the survey results and in the indirect cost calculations. Below, we describe the key aspects of the sample characteristics. Indirect cost estimates will be shown in the Results section.

### *Survey Sample Characteristics*

As shown in **Exhibit II-4**, after weighting, about 10% of the survey respondents had the first symptoms of MS begin in the past 5 years, 13% had symptoms begin between 5 and 9 years ago, 16% had symptoms begin 10 to 14 years ago, and 15% had symptoms begin 15 to 19 years ago. A little over 46% of the respondents had their first symptoms begin 20 or more years ago, representing a significant proportion of the survey population. There is a lag of almost 6 years between the occurrence of the first symptoms and the initial diagnosis. For example, after weighting, about 18% of the survey respondents were diagnosed with MS in the past 5 years (compared to about 10% of persons with MS who experienced the first symptoms in the past 5 years); 19% were diagnosed between 5 and 9 years ago, 18% were diagnosed between 10 to 14 years ago, and 15% were diagnosed between 15 to 19 years ago. A little over 29% of the respondents were diagnosed 20 or more years ago, representing a significant proportion of the survey population. For an average person with MS, the duration of MS since the first symptoms was 19.8 years and 14.4 years since the MS diagnosis.

**Exhibit II-4. Disease duration since first symptom and since diagnosis for persons with MS**

	Unweighted		Weighted	
	Frequency	Percent	Frequency	Percent
<b>Duration since the first symptom</b>				
Less than 5 years	102	10.8	94,106	9.8
5-9 years	133	14.1	123,519	12.8
10-14 years	159	16.8	153,574	15.9
15 -19 years	148	15.6	146,981	15.2
20 years or more	404	42.7	447,003	46.3
<b>Total</b>	<b>946</b>	<b>100</b>	<b>965,184</b>	<b>100</b>
<b>Mean (No. of Years)</b>	18.7		19.8	
<b>Duration since diagnosis</b>				
Less than 5 years	187	19.8	174,801	18.1
5-9 years	189	20.0	180,373	18.7
10-14 years	179	18.9	177,973	18.4
15 -19 years	142	15.0	148,467	15.4
20 years or more	249	26.3	283,569	29.4
<b>Total</b>	<b>946</b>	<b>100</b>	<b>965,184</b>	<b>100</b>
<b>Mean (No. of Years)</b>	13.6		14.4	

Source: Primary data collected through the MS Impact Survey.

A main purpose of the survey was to estimate the caregiver burden. Therefore, it is important to understand the extent to which persons with MS are receiving care from an unpaid caregiver(s). As shown in **Exhibit II-5**, after weighting, 54% of persons with MS reported that they had received care from a primary caregiver (PC) in 2019, and nearly 19% of persons with MS received unpaid care from a secondary caregiver (SC).

**Exhibit II-5. Percentage of persons with MS who received unpaid care from a caregiver in 2019**

		Unweighted		Weighted	
		Frequency	Percent	Frequency	Percent
Received Care from a Primary Caregiver (PC)	<b>Total</b>	<b>946</b>	<b>100</b>	<b>965,184</b>	<b>100</b>
	Yes	506	53.5	522,371	54.1
	No	440	46.5	442,813	45.9
Received Care from a Secondary Caregiver (SC)	<b>Total</b>	<b>946</b>	<b>100</b>	<b>965,184</b>	<b>100</b>
	Yes	178	18.8	179,485	18.6
	No	768	81.2	785,699	81.4

Source: Primary data collected through the MS Impact Survey.

**Exhibit II-6** shows the demographic and socioeconomic characteristics of persons with MS and their caregivers. After weighting, about 50% of persons with MS were between age 45 and 64, 74% were females, and 87% were White or Caucasian. Looking at the age profile of the caregivers, a vast majority of them were young: only about 31% of the PCs and 23% of the SCs were over age

65. It is not entirely surprising that about 50% of PC were aged 45-64 and about half of SCs were younger than 45. This is consistent with the assumption that the PCs are more likely to be spouses, while the SCs – adult children. Given that the prevalence of MS is higher among women, the gender breakdown of caregivers is in line with the expectation that PCs are more likely to be male and SCs are more likely to be female, with 64% of PCs being male and 61% of SCs being female. Similar to the demographic profile of the person with MS, more than 80% of the PCs and SCs were White or Caucasian; the American Indian or Alaska Native, Asian, and Native Hawaiian or Other Pacific Islander groups were all represented at low percentages in the survey.

**Exhibit II-6. Baseline characteristics of the persons with MS and unpaid caregivers**

			Unweighted			Weighted		
			MS	PC	SC	MS	PC	SC
<b>All</b>			<b>946</b>	<b>506</b>	<b>178</b>	<b>965,184</b>	<b>522,371</b>	<b>179,485</b>
<b>Age</b>	<45	N	294	118	84	255,841	107,929	83,046
		%	31.1	23.3	47.2	26.5	20.7	46.3
	45-64	N	492	255	54	483,595	250,899	55,153
		%	52.0	50.4	30.3	50.1	48.0	30.7
	65-74	N	139	109	23	177,359	127,274	23,703
		%	14.7	21.5	12.9	18.4	24.4	13.2
	≥75	N	21	24	17	48,389	36,269	17,583
		%	2.2	4.7	9.6	5.0	7.0	9.8
<b>Gender</b>	Female	N	733	169	110	718,195	186,162	108,649
		%	77.5	33.4	61.8	74.4	35.6	60.5
	Male	N	207	332	62	246,989	334,321	65,171
		%	21.9	65.6	34.8	25.6	64.0	36.3
	Prefer not to say	N	6	5	6	0	1,888	5,665
		%	0.6	1.0	3.4	0.0	0.4	3.2
<b>Race / Ethnicity</b>	American Indian or Alaska Native	N	6	2	1	5,751	2,245	1,301
		%	0.6	0.4	0.6	0.6	0.4	0.7
	Asian	N	5	6	0	4,646	6,380	0
		%	0.5	1.2	0.0	0.5	1.2	0.0
	Black or African American	N	72	30	18	68,641	28,248	16,811
		%	7.6	5.9	10.1	7.1	5.4	9.4
	Multi-racial	N	19	13	8	17,956	12,212	7,344
		%	2.0	2.6	4.5	1.9	2.3	4.1
	Native Hawaiian or Other Pacific Islander	N	2	0	0	1,888	0	0
		%	0.2	0.0	0.0	0.2	0.0	0.0
	White or Caucasian	N	809	433	144	836,780	453,686	147,199
		%	85.5	85.6	80.9	86.7	86.9	82.0
	Other	N	17	12	4	17,661	11,739	3,998

			Unweighted			Weighted		
			MS	PC	SC	MS	PC	SC
		%	1.8	2.4	2.3	1.8	2.3	2.2
	Prefer not to say	N	16	10	3	11,860	7,861	2,832
		%	1.7	2.0	1.7	1.2	1.5	1.6

Source: Primary data collected through the MS Impact Survey. MS: Persons with MS. PC: Primary caregivers. SC: Secondary caregivers.

**Exhibit II-7** shows the age and gender breakdown for persons with MS and unpaid caregivers (stratification shows each person's own age and gender). Nearly 60% of persons with MS were females younger than 65 years of age (i.e., 37% were women aged 45-64 and 19% were women aged 18-44). The corresponding share of males with MS in the same age group was only 20%, with 13% being age 45-64 and 7% being age 18-44. The gender-age profile of caregivers shows the opposite: while the majority of persons with MS were females younger than 65, 43% of primary caregivers were males age 18-64 and another 16% were males age 65-74. Among secondary caregivers 26% were females 18-44 years of age and 20% were males 18-44 years of age. The gender-age profile is consistent with the fact that primary caregivers tend to be spouses and partners of person with MS, whereas secondary caregivers represent a younger generation.

See Appendix E for additional data on the socio-economic and disease characteristics of the MS Impact Survey respondents.

**Exhibit II-7. Persons with MS and unpaid caregivers by age and gender**

			Unweighted			Weighted		
			MS	PC	SC	MS	PC	SC
<b>All</b>			<b>940</b>	<b>506</b>	<b>178</b>	<b>965,184</b>	<b>522,371</b>	<b>179,485</b>
<b>Male</b>	18-44	N	60	76	35	68,957	64,545	35,369
		%	6%	15%	20%	7%	12%	20%
	45-64	N	107	171	14	121,993	160,976	15,026
		%	11%	34%	8%	13%	31%	9%
	65-74	N	36	70	6	44,662	83,050	7,910
		%	4%	14%	3%	5%	16%	5%
	≥75	N	4	15	7	11,377	25,750	6,866
		%	0%	3%	4%	1%	5%	4%
<b>Female</b>	18-44	N	231	41	47	186,884	43,384	45,788
		%	25%	8%	27%	19%	8%	26%
	45-64	N	383	82	38	361,602	88,979	38,239
		%	41%	16%	22%	37%	17%	22%
	65-74	N	102	38	16	132,697	44,224	14,848
		%	11%	8%	9%	14%	8%	9%
	≥75	N	17	8	9	37,012	9,575	9,773
		%	2%	2%	5%	4%	2%	6%

Source: Primary data collected through the MS Impact Survey. MS: Persons with MS. PC: Primary caregivers. SC: Secondary caregivers. Stratification of data is done by each person's own gender and age group. Six persons with MS did not disclose their gender; they are excluded from this table.

### ***Labor Market Employment Related Earnings Loss***

MS may increase the likelihood that severe functional impairment or disability will prevent persons with MS from working, or in some cases limit employment opportunities and reduce earnings. In a recent Finnish study, Heinonen et al (2020) found that patterns of early retirement due to MS have changed since the introduction of DMT.<sup>24</sup> Specifically, the rate of retirement due to MS in Finland has decreased significantly since the introduction of DMT in 1995 and the median time from diagnosis to retirement has become longer. They also found that not using DMT for relapsing-remitting MS was identified as one risk factor for losing ability to work prematurely.

An analysis of our primary survey found that among working age (18-64) persons with MS, 58.7% were in the labor market, as compared to the national labor force participation rate of 63.1% among the U.S. adult population. To ensure that the early termination of employment was a direct result of MS, we asked survey respondents who had retired or stopped working if MS played a major role in their decision to terminate employment. Consequently, the labor market employment related earnings loss due to MS was calculated as the counts of persons with MS who had retired or stopped working in the past 12 months and indicated that MS played a major role in their early retirement decision [*Question 26 and Questions 26a-c*] multiplied with the median annual earnings obtained from the 2019 American Community Survey (ACS) public use microdata sample. The analysis was done by age group, gender, and job status (full-time versus part-time).

As the job status (full-time versus part-time) of persons with MS before retirement was unknown, we used the allocation of full-time to part-time job status among currently working persons with MS (for corresponding age and gender strata) [*Question Q25*]. Then, we calculated earnings loss due to early retirement separately for those who retired due to MS and were assumed to be working full-time before retirement and for those who were assumed to be working part-time before retirement.

### ***Labor Market Productivity Loss***

A chronic disease like MS is likely to result in lower productivity while the person with MS and the caregivers are employed. The measure of reduced productivity conditional on being employed consists of two key measures: (1) absenteeism, i.e., increased workdays missed due to illness; and (2) presenteeism, i.e., illness-related poorer work performance while on the job. Productivity losses typically refer to either losses related to labor market activity or social activity, and are different from the intangible cost, which usually includes things such as pain, reduced quality of life, etc.

Two questions in the MS Impact Survey asked about the number of days in an average working month during 2019 the person with MS and the caregivers missed work at a job or business or felt less productive while at work, because of MS [*Questions 29 & 30*]. Based on responses to these two questions and the average daily earnings calculated from the self-reported annual earnings [*Question 18*], we calculated the productivity loss due to absenteeism by multiplying the number of days missed with the daily earnings and then annualized the total loss. Presenteeism was calculated similarly, with an adjustment factor applied to each day felt unproductive, reflecting that an unproductive day is not equivalent to a total loss of a whole day's value. The estimated days lost



due to presenteeism was then multiplied with the daily earnings from the survey sample who were employed in the past year and annualized to the total loss in 2019. The adjustment factor was obtained from the respondents' responses to productivity self-assessment scale: i.e., on days when feel less productive, on average how productivity of persons with MS and caregivers was affected on a scale from 0 to 10, where 0 represents "not at all", 1-3 "mildly", 4-6 "moderately", 7-9 "markedly", and 10 represents "extremely" [Question 30a]. This number was translated into the reduced overall productivity (e.g., 0 corresponds to 100% productivity, 5 corresponds to 50% productivity, etc.).

As Question 18 of the MS survey did not ask about exact annual earnings, but rather asked respondents to indicate which annual earnings bracket was applicable, we converted these categorical responses into numerical values based on the mid-point of each earnings category (e.g., everyone who indicated earnings "less than \$1,000" were assigned earnings of \$500; everyone in "\$1,000 to less than \$25,000" were assigned \$12,000; etc.).

### ***Productivity Loss from Forgone Social Activities***

In addition to affecting labor market productivity for those who are currently employed, MS may also affect the extent to which persons with MS and the caregivers are able to participate in various social activities using their leisure time. Given that 70% (weighted sample response from the MS survey) of the MS population were older (age 45-74) and about 45% of persons with MS were retired, lower probability of employment and other job-related indicators might not capture the true impact of MS on productivity loss for the older persons with MS and caregivers who are not working. Even for persons with MS and caregivers who were still working, the effect of MS may cause them to forgo leisure activities to better cope with the disease. However, the productivity loss due to forgone social activities because of MS has been largely neglected in the literature.

To measure time lost from forgone social activities, we asked a question on the number of hours the person with MS [Question 32] and the caregivers [Question 32a and Question 32b] spent in a typical week before and after MS started having a significant impact, on the following social activities:

1. Performing voluntary or charity work
2. Providing help to family, friends, or neighbors unrelated to personal care or care for persons with MS
3. Participating in a political or community-based organization

The challenge in quantifying social productivity loss lies in the difficulty of measuring the time forgone from social activities as well as in the proper valuation of the time forgone. Although one could argue that forgone leisure time on activities such as visiting family and friends also creates economic loss, it was our intention to only capture the economic loss due to reduced economic production of each individual that directly contributed to societal benefits. Therefore, in our social productivity loss related calculations, we focused on activities listed above that are considered directly involving volunteer work and provided a conservative estimate of the social productivity loss.

To evaluate the plausibility of reported hours conducting volunteering work, we compared the reported volunteering hours before MS with the average national annual volunteering hours obtained from the Current Population Survey (CPS) Volunteer Supplement Survey that measures



the population's participation in volunteer activities (2017). The comparison indicated that the national average volunteering hours are generally lower than the volunteering hours reported in the MS Impact Survey (e.g., the average national volunteering hours are 1.9 hours per week [98 hours per-year] and the average hours in the MS survey for persons with MS before MS are 16.1 hours per week). Therefore, we took a conservative approach in our calculations by calculating the age-gender specific percentage volunteered and average hours volunteered from CPS and multiplied it with the estimated percentage productivity loss from the MS Impact Survey (calculated as the difference between before and after hours divided by before hours) for the three activities combined.

To place a dollar value on foregone volunteering activities, we used the \$27.20 per hour in 2019 dollars estimated by the Independent Sector.<sup>25</sup> Productivity loss due to foregone volunteering activities was then calculated as: volunteering hours affected per year times \$27.20.

### C. Estimating Non-Medical Costs

Data from the MS Impact Survey also helped to inform additional personal and family costs associated with MS that are not captured in administrative data or national surveys. These non-medical costs that are not covered by insurance or provided by charitable organizations include expenses of purchasing formal care (e.g., adult day care and personal aides) and modification to homes, purchases of special motor vehicles, food, or dietary supplements, and increased travel costs for medical visits, as well as medical tourism. *Question 23* of the MS survey asked about the amount that the person with MS or the family had spent in 2019 on 4 major non-medical cost categories, as a result of caring for the person with MS. These 4 non-medical cost categories include the total \$ amount paid for: 1) hiring someone to provide daily assistance, 2) making home modifications, 3) purchasing a special vehicle or purchasing/installing special equipment on a car or other motor vehicle, and 4) increased transportation costs (e.g. driving to and from clinics, rehab facilities, travel out of country for treatment, etc.). We examined the cost distribution for each category to evaluate the presence of outlier observations. High-cost outliers can skew distribution to the right and inflate the mean. We compared mean and median and per discussions with NMSS and decided to use more conservative median expenditures for each cost category.

We estimated the total national cost of such non-medical components 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.

### D. Estimating the Medical Costs Not Covered by Insurance

Although we believe that most medical costs associated with MS are captured in our analyses of claims data, we wanted to account for non-traditional healthcare services that might not be covered by insurance. *Question 21* of the MS survey asked about the amount that the person with MS or the family had spent in 2019 on the following healthcare-related services/treatments:

1. Medical cannabis for MS-related symptoms
2. Experimental treatments (e.g., Hematopoietic Stem Cell therapy (HSCT)) related to MS
3. Alternative or non-traditional treatments (alternative therapies, massage therapy, acupuncture) related to MS

Similar to non-medical costs, we used median expenditures for this cost component. We estimated the total national cost of medical costs not covered by insurance 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.

## E. Disability Income

In addition to the economic burden of a disease to individuals, families, and society as a whole, certain *costs* are incurred by the government, even though these are not entirely lost resources since the funds are transferred from one entity to another. In order to capture the overall burden of a disease, it is always an important policy perspective to be able to identify the extent to which individuals are transitioning into public programs, and what the potential costs to public programs are due to any specific condition/disease, particularly if these costs are avoidable. For example, Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) are considered as transfer payments (i.e., a cost to one person is a benefit to another person), and therefore, these components may inform on the extent of government budgetary burden due to a specific disease, such as MS. In the MS survey, we asked a combined question (*Question 19 and 19a*) on whether the person with MS had received SSI, SSDI, or other types of disability income (OTDI), in 2019. The OTDI captures income from state disability insurance, VA benefits/VA disability compensation, long-term disability benefit from the last employer, etc. Based on the proportion of persons with MS who answered “yes” and the average yearly amount received from each source of these disability income, we estimated the median and total disability income due to MS.

## III. Results

### A. Multiple Sclerosis Prevalence

**Exhibit III-1** presents the prevalence of MS by population characteristics. An estimated 1 million individuals in the U.S. had MS in 2019. The prevalence of MS increases with age and peaks for the 45-65 age group; this age group represents the largest share (50%) of the MS population. While the prevalence among those younger than 45 years is low (0.22%), this age group represents the second largest group in the MS population (nearly 30%). Females have a higher prevalence than males, 0.55 percent and 0.20 percent respectively (or 549 males and 199 females per 100,000 people, respectively); females also represent 74% of the MS population.

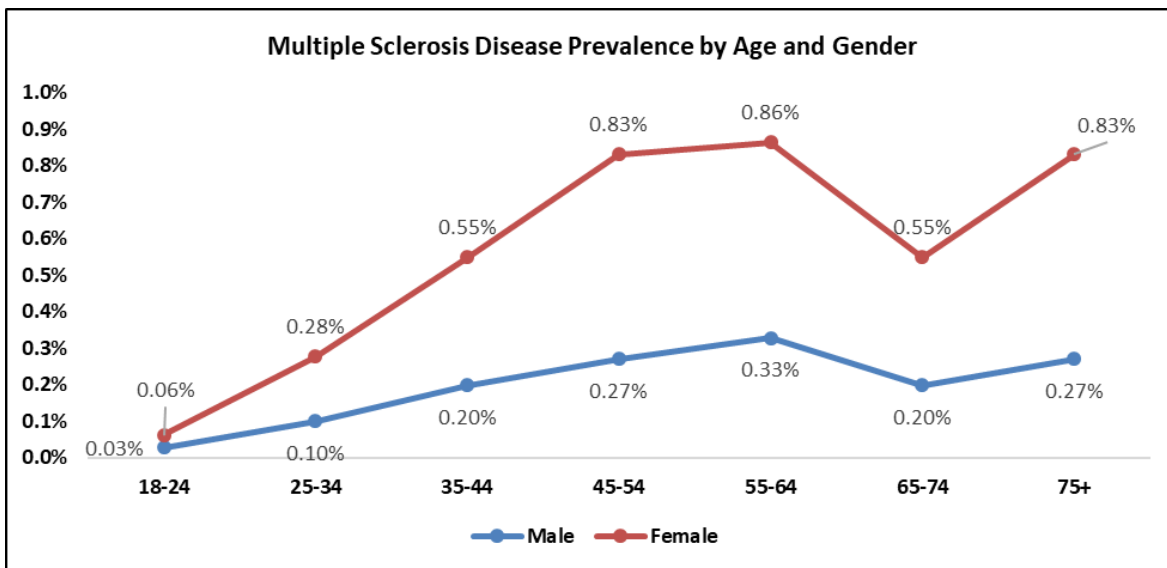
### Exhibit III-1. MS prevalence by population characteristics

	No. of Persons Estimated to Have MS	Percent of Total MS population	Population	Prevalence	Prevalence per 100,000 people
<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). We applied the annual growth factor of 2.3% to the 2010 estimates to calculate prevalence in 2019.

**Exhibit III-2** shows the prevalence of MS by gender and smaller age groups. The prevalence pattern is similar for male and female, albeit is much higher for females for all ages except age 18-24.

### Exhibit III-2. MS disease prevalence by age and gender



## B. Direct Medical Cost

**Exhibit III-3** presents the direct medical cost of MS by age and gender. When compared to a matched comparison group, the direct costs for individuals with MS are substantially higher by age, gender, and insurance coverage (see **Exhibit B-2** in Appendix B). Males, although incurring slightly higher per-person costs than females with MS, had a lower overall direct medical cost burden, due to the higher prevalence of MS among females.

**Exhibit III-3. Direct medical cost of MS by age and gender**

	Total Excess Medical Cost		Mean Excess Cost due to MS (\$)
	Excess Cost (in Million \$s)	Percentage of Total	
<b>Males</b>			
18-44 years	\$4,876	7.7%	\$70,713
45-64 years	\$8,724	13.8%	\$71,514
≥65 years	\$3,838	6.1%	\$68,485
<b>Females</b>			
18-44 years	\$11,678	18.4%	\$62,488
45-64 years	\$23,788	37.6%	\$65,785
≥65 years	\$10,424	16.5%	\$61,422
<b>Overall</b>	<b>\$63,183</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, 2019 Medicare Standard Analytical File 5% sample claims, and 2018 Medicare Current Beneficiary Survey (MCBS).

**Exhibits III-4** breaks down the total excess medical cost of MS by types of service. The analysis of direct medical costs by type of service for persons with MS indicated that prescription medication is the costliest component when compared to other service types. When compared with their matched comparison group, persons with MS experience a total average excess medical costs of \$65,612.

**Exhibit III-4. Direct medical cost by types of service**

	Total Excess Medical Cost (in Million \$s)	Per Person Medical Cost (\$)
Hospital inpatient	\$3,910	\$4,051
Non-acute institutional care	\$1,568	\$1,624
Outpatient medication and administration	\$7,768	\$8,049
Outpatient facilities	\$5,537	\$5,737
Physician office	\$4,636	\$4,803
Durable medical equipment	\$252	\$262
Other ancillary	\$1,728	\$1,790
Prescription medication without DMT	\$3,999	\$4,143
Prescription medication DMT	\$33,930	\$35,154
<b>Total</b>	<b>\$63,328</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, 2019 Medicare Standard Analytical File 5% sample claims, and 2018 Medicare Current Beneficiary Survey (MCBS). DMT: Disease-modifying therapy.

Beside prescription medication, outpatient medication and administration, as well as outpatient facilities are type of services with high per person costs. The usage of DMT varies substantially by

age group and not all MS patients are treated with DMT. About 50% of adults age 18-64 with MS are treated with DMT (**Exhibit A-1** in Appendix A). However, usage is lower among the Medicare population: 40% of females and about 20% of males. Therefore, cost per person with MS who uses DMT is high and ranges from \$57,202 to \$92,719 depending on gender-age strata.

## C. Indirect Costs

### *Premature Death-related Future Earnings Loss*

**Exhibit III-5** below presents the estimated future earnings loss associated with premature deaths due to MS for people with MS (stratification is by age and gender of persons with MS). As anticipated, the average present value of future earnings per death decreases with age because of the shorter timespan between the age of death and the expected life span for older patients. Men have higher loss per death because males have higher labor force participation rates and average earnings compared to females. In summary, we estimate an average of \$338,585 in lost earnings per premature death for a total of \$8.0 billion.

**Exhibit III-5. Estimated net present value of the future earnings loss for premature deaths associated with MS**

	Estimated Number of Premature Deaths	Estimated Present Value of Future Earnings/Death (\$)	Estimated NPV (in Million \$s)
<b>Males</b>	<b>5,768</b>	<b>376,946</b>	<b>2,174</b>
18-44 years	689	1,035,341	713
45-64 years	3,049	439,785	1,341
65-74 years	2,030	59,150	120
<b>Females</b>	<b>17,963</b>	<b>326,267</b>	<b>5,861</b>
18-44 years	2,071	886,793	1,837
45-64 years	10,004	377,438	3,776
65-74 years	5,888	42,151	248
<b>Overall</b>	<b>23,732</b>	<b>338,585</b>	<b>8,035</b>

Source: Lewin analyses of 2015-2017 CDC Wonder and 2018 Medicare 5% sample claims data. Death rates for ≥65 were derived from Medicare 5% data. Death rates for <65 non-MS population were derived from CDC WONDER data. Death rates for <65 MS population are estimated. Average earnings by age and gender obtained from Bureau of Labor Statistics.

### *Labor Market Employment Related Earnings Loss*

In reference to employment status, 0.5% of persons with MS and 1.2% of primary caregivers reported that they had retired in 2019 and MS played a major role in their decision to stop working. Among the secondary caregivers, there were no respondents who retired in 2019. The total estimated earnings loss due to MS related to early retirement was \$600 million for persons with MS and \$243 million for PCs. Among persons with MS, the highest earnings loss was for people age 45-64, especially females due to the higher MS prevalence among this group (**Exhibit III-6**).

**Exhibit III-6. Estimated labor market earnings loss due to MS related retirement in 2019**

	Persons with MS (919)		Primary Caregivers (478)		Secondary Caregivers (156)	
	Percentage Retired and Stopped Working due to MS	Total Earnings Loss (in Million \$s)	Percentage Retired and Stopped Working due to MS	Total Earnings Loss (in Million \$s)	Percentage Retired and Stopped Working due to MS	Total Earnings Loss (in Million \$s)
<b>Males</b>	<b>1.9%</b>	<b>138.5</b>	<b>0.9%</b>	<b>140.6</b>	<b>0.0%</b>	<b>0</b>
18-44 years	0.0%	0	1.5%	40.2	0.0%	0
45-64 years	1.9%	138.5	0.6%	56.0	0.0%	0
65-74 years	0.0%	0	1.1%	44.3	0.0%	0
<b>Females</b>	<b>1.7%</b>	<b>461.4</b>	<b>1.6%</b>	<b>102.1</b>	<b>0.0%</b>	<b>0</b>
18-44 years	2.2%	144.9	0.0%	0.0	0.0%	0
45-64 years	2.1%	316.5	2.0%	73.2	0.0%	0
65-74 years	0.0%	0	2.6%	28.9	0.0%	0
<b>Overall</b>	<b>0.5%</b>	<b>599.9</b>	<b>1.2%</b>	<b>242.7</b>	<b>0.0%</b>	<b>0.0</b>

Source: Primary data collected through the MS Impact Survey, combined with average earnings from Bureau of Labor Statistics, and the published MS prevalence estimates. Adults 75 and older are assumed to be out of labor force and hence losses are calculated only for adults <75. Stratification in the table is done by person's own age and gender.

***Labor Market Productivity Loss***

Exhibit III-7 displays the percentage of persons with MS and their unpaid caregivers who were employed in 2019. For MS, PC, and SCs alike, the probability of labor market employment decreased with age and in general was higher among male adults younger than 65 than among females of similar age.

**Exhibit III-7. Percentage of persons with MS and unpaid caregivers employed in 2019**

	Persons with MS		Primary Caregivers		Secondary Caregivers	
	Total Population	% Employed	Total Population	% Employed	Total Population	% Employed
<b>Males</b>	<b>235,612</b>	<b>48%</b>	<b>308,571</b>	<b>73%</b>	<b>58,305</b>	<b>70%</b>
18-44 years	68,957	70%	64,545	89%	35,369	69%
45-64 years	121,993	49%	160,976	83%	15,026	88%
65-74 years	44,662	9%	83,050	32%	7,910	39%
<b>Females</b>	<b>681,183</b>	<b>45%</b>	<b>176,587</b>	<b>58%</b>	<b>98,876</b>	<b>60%</b>
18-44 years	186,884	67%	43,384	69%	45,788	58%
45-64 years	361,602	49%	88,979	64%	38,239	68%
65-74 years	132,697	4%	44,224	28%	14,848	44%
<b>Overall</b>	<b>916,795</b>	<b>46%</b>	<b>485,158</b>	<b>68%</b>	<b>157,181</b>	<b>64%</b>

Source: Primary data collected through the MS Impact Survey, combined with the published MS prevalence estimates. Percent employed includes both part-time and full-time employed. Adults 75 and older are assumed to be out of the labor force. Stratification in the table is done by each person's own age and gender.

As shown in **Exhibit III-8**, males with MS on average lost fewer workdays in a typical working month than females with MS, except for the oldest age group (65-74 years). While male PCs in the youngest age group lost more days from work than female PCs of similar age, the older female PCs in general lost more workdays than their male counterparts did. On average, the person with MS lost more workdays (4 days) than both the PC (3.0 days) and the SC group (1.6 days) groups. The total annual absenteeism was highest for persons with MS (\$3.4 billion), followed by PCs (\$1.8 billion), and the SCs (\$270 million).

**Exhibit III-8. Estimated productivity loss due to MS related absenteeism for those younger than 75 (in million \$s)**

	Persons with MS		Primary Caregivers		Secondary Caregivers	
	Average No. of Work Days Missed	Total Annual Absenteeism Cost (in Million \$s)	Average No. of Work Days Missed	Total Annual Absenteeism Cost (in Million \$s)	Average No. of Work Days Missed	Total Annual Absenteeism Cost (in Million \$s)
<b>Males</b>	<b>2.9</b>	<b>890.0</b>	<b>2.9</b>	<b>1,279.2</b>	<b>0.6</b>	<b>30.4</b>
18-44 years	3.3	430.8	3.5	398.8	0.6	12.2
45-64 years	2.1	421.2	2.9	768.3	0.7	18.2
65-74 years	7.8	38.0	2.2	112.1	0.0	0.0
<b>Females</b>	<b>4.2</b>	<b>2,559.0</b>	<b>3.2</b>	<b>552.6</b>	<b>2.3</b>	<b>239.4</b>
18-44 years	5.0	1,257.1	2.9	103.4	1.3	38.8
45-64 years	3.7	1,285.1	3.6	412.3	3.7	193.0
65-74 years	2.5	16.8	2.4	36.9	0.9	7.6
<b>Overall</b>	<b>3.8</b>	<b>3,449.0</b>	<b>3.0</b>	<b>1,831.9</b>	<b>1.6</b>	<b>269.8</b>

Source: Primary data collected through the MS Impact Survey, combined with the published MS prevalence estimates. Adults 75 and older are assumed to be out of the labor force. Stratification in the table is done by person's own age and gender.

As shown in **Exhibit III-9**, in a typical working month, persons with MS on average had about 10 days feeling less productive than individuals without MS and this was because of MS; followed by PCs (6.0 days) and SCs (2.8 days). Among working age adults with MS, males had slightly fewer unproductive days compared to working age females with MS. To take a conservative approach, we did not count the full number of days that felt less productive in the presenteeism calculations, rather we assumed that only a certain portion of the unproductive days was due to MS. Therefore, we applied an adjustment based on a self-productivity assessment scale described in the method section. Based on this approach and when multiplied with the average earnings data, the annual presenteeism was estimated to be close to \$4.2 billion for persons with MS, \$1.5 billion for PCs, and \$146 million for SCs.



**Exhibit III-9. Estimated productivity loss due to MS disease related presenteeism for those younger than 75 (in million \$s)**

	Persons with MS		Primary Caregivers		Secondary Caregivers	
	Average No. of Work Days Less Productive	Total Annual Presentism Cost (in Million \$s)	Average No. of Work Days Less Productive	Total Annual Presentism Cost (in Million \$s)	Average No. of Work Days Less Productive	Total Annual Presentism Cost (in Million \$s)
<b>Males</b>	<b>9.1</b>	<b>1,252.6</b>	<b>6.1</b>	<b>1,098.2</b>	<b>1.1</b>	<b>15.2</b>
18-44 years	9.6	599.8	7.1	321.7	1.4	8.2
45-64 years	8.0	615.4	6.2	651.6	0.7	7.0
65-74 years	15.3	37.4	4.6	124.9	0.0	0.0
<b>Females</b>	<b>10.8</b>	<b>2,990.6</b>	<b>5.7</b>	<b>408.2</b>	<b>3.8</b>	<b>130.4</b>
18-44 years	12.4	1,482.6	5.1	89.3	4.1	43.3
45-64 years	10.0	1,491.2	5.4	251.2	4.0	75.4
65-74 years	5.0	16.8	8.5	67.7	1.4	11.7
<b>Overall</b>	<b>10.0</b>	<b>4,243.4</b>	<b>6.0</b>	<b>1,506.5</b>	<b>2.8</b>	<b>145.5</b>

Source: Primary data collected through the MS Impact Survey, combined with MS prevalence from the published literature. Adults 75 and older are assumed to be out of the labor force. Stratification in the table is done by person's own age and gender.

***Productivity Loss from Forgone Social Activities***

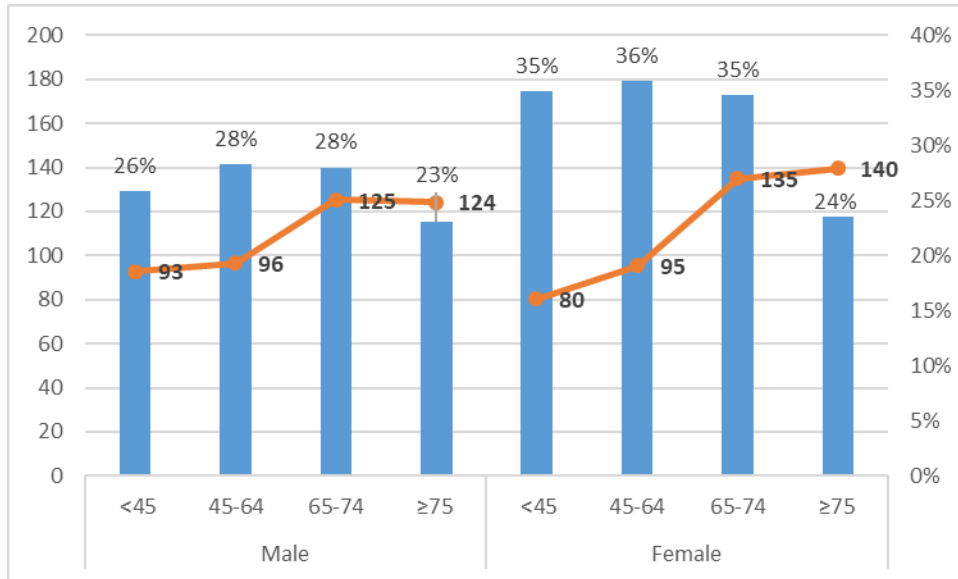
The impact of MS on social productivity was measured based on the reduction in the individual's ability to perform volunteering work in the following activities:

1. Performing voluntary or charity work
2. Providing help to family, friends, or neighbors unrelated to personal care
3. Participating in a political or community-related organization

Although the survey questions were designed to capture hours spent on each activity independently, the total self-reported volunteering hours were 4-9 times higher than the national numbers, depending on the group (e.g., persons with MS or caregivers) or the time period (BEFORE to AFTER MS started to have a major impact) being examined. Therefore, to make a more objective estimate, we relied on the Volunteer Supplement of the Current Population Survey in 2017 to calculate the percentage of individuals who volunteer in a year and the average number of hours volunteered. Social productivity reduction was calculated as the percentage reduction in the hours spent on volunteer activities from BEFORE to AFTER MS started to have a major impact, calculated based on the responses to the MS Impact Survey. We then applied the social productivity reduction (in percentages) to the average hours each individual expected to volunteer, based on his or her age and gender, and without the impact of MS, to calculate the hours lost from volunteering activities due to MS. The estimated hours lost due to MS were then multiplied by the average value of each volunteer hour of \$27.20 as estimated by the Independent Sector to quantify the economic value of social productivity loss.<sup>25</sup>

**Exhibit III-10** shows that a higher percentage of U.S. female adults perform volunteer work than males. However, working age females spend fewer hours volunteering than males among those who do volunteer. Regardless of gender, older Americans ( $\geq 65$  years) tend to spend more hours volunteering.

**Exhibit III-10: Percentage of Americans volunteered in the past 12 months and the average number of hours volunteered**



Source: Lewin’s analysis of the Current Population Survey Volunteer Supplement (2017).

**Exhibit III-11** shows that across age and gender and for both persons with MS and their caregivers, MS leads to a significant reduction in individuals’ ability to perform volunteer work relative to the time before MS. These changes ranged from a 24% (or 3.2 hours) reduction among the SCs to a 58% (or 9.4 hours) reduction among persons with MS. Overall monetary value of lost social productivity was \$474 million for persons with MS, \$149 million for PCs, and close to \$37 million for SCs.

### Exhibit III-11. Estimated social productivity loss due to MS

	Persons with MS		Primary Caregivers		Secondary Caregivers	
	Average Change in Hours (% reduction from before MS impact)	Total Annual Social Productivity Loss (in Million \$s)	Average Change in Hours (% reduction from before MS impact)	Total Annual Social Productivity Loss (in Million \$s)	Average Change in Hours (% change from before MS impact)	Total Annual Social Productivity Loss (in Million \$s)
<b>Males</b>	<b>7.0 (54%)</b>	<b>91.7</b>	<b>5.0 (41%)</b>	<b>101.4</b>	<b>3.2 (26%)</b>	<b>11.4</b>
18-44 years	5.7 (48%)	22.0	5.4 (50%)	21.6	2.0 (16%)	3.7
45-64 years	9.9 (61%)	53.8	6.1 (45%)	51.5	0.6 (8%)	0.9
≥65 years	2.6 (32%)	15.9	3.1 (29%)	28.3	8.8 (51%)	6.8
<b>Females</b>	<b>10.2 (59%)</b>	<b>382.2</b>	<b>4.1 (30%)</b>	<b>47.9</b>	<b>3.3 (24%)</b>	<b>25.3</b>
18-44 years	12.4 (67%)	95.4	3.9 (36%)	12.1	3.1 (35%)	12.2
45-64 years	10.9 (60%)	202.1	5.9 (36%)	29.5	0.5 (3%)	1.1
≥65 years	6.4 (46%)	84.7	1.3 (11%)	6.3	8.0 (45%)	12.0
<b>Overall</b>	<b>9.4 (58%)</b>	<b>473.8</b>	<b>4.6 (37%)</b>	<b>149.3</b>	<b>3.2 (24%)</b>	<b>36.7</b>

Source: Lewin’s analysis of the Current Population Survey Volunteer Supplement (2019), combined with primary data collected through the MS Impact Survey, and the published MS prevalence estimates. Stratification in the table is done by person’s own age and gender.

## D. Non-Medical Costs and Services Not Covered by Insurance

### Non-Medical Costs

The percentage of persons with MS who hired someone to provide daily care or assistance and the amount spent per person with MS generally increased with age. In total, persons with MS age 65 years or older spent the most on daily care. Overall, \$247 million was spent on this cost component (Exhibit III-12).

### Exhibit III-12. Estimated formal non-medical care costs due to MS

	% of Persons with MS Who Hired Someone to Provide Daily Care in the Past 12 Month	Median Cost (\$)	Total Cost of Paid Non-Medical Care (in Million \$s)
<b>Males</b>	<b>8%</b>	<b>2,150</b>	<b>52.3</b>
18-44 years	8%	500	2.9
45-64 years	7%	2,150	19.6
≥65 years	9%	6,000	29.8
<b>Females</b>	<b>6%</b>	<b>2,400</b>	<b>194.6</b>
18-44 years	2%	2,200	7.1
45-64 years	4%	1,520	24.4
≥65 years	12%	8,000	163.1

	% of Persons with MS Who Hired Someone to Provide Daily Care in the Past 12 Month	Median Cost (\$)	Total Cost of Paid Non-Medical Care (in Million \$s)
<b>Overall</b>	<b>7%</b>	<b>4,149</b>	<b>246.9</b>

Source: Primary data collected through the MS Impact Survey, combined with the published MS prevalence estimates.

**Exhibit III-13** shows the percentage of persons with MS who incurred other non-medical costs. About 17% of persons with MS or their family incurred expenses on home modifications (e.g., building a ramp in place of steps to enter/exit home); 26% on purchasing/installing special equipment on a personal vehicle or at home; and 43% had increased transportation costs for reasons such as driving to and from clinics, rehab facilities, medical tourism, etc. Overall, persons with MS and their families spent close to \$506 million on the three key components of the non-medical cost categories.

**Exhibit III-13. Estimated non-medical costs due to MS**

	Home Modification Cost		Special equipment at home or in vehicle		Increased Transportation Costs		Total Cost (in Million \$s)
	% of Persons with MS with the Expense	Median Cost (\$)	% of Persons with MS with the Expense	Median Cost (\$)	% of Persons with MS with the Expense	Median Cost (\$)	
<b>Males</b>	<b>20%</b>	<b>1,500</b>	<b>24%</b>	<b>1,450</b>	<b>41%</b>	<b>360</b>	<b>177.1</b>
18-44 years	10%	1,750	12%	1,500	38%	360	33.7
45-64 years	23%	1,500	26%	1,450	36%	400	106.8
≥65 years	23%	500	35%	1,020	55%	340	36.6
<b>Females</b>	<b>16%</b>	<b>800</b>	<b>28%</b>	<b>500</b>	<b>43%</b>	<b>300</b>	<b>328.5</b>
18-44 years	12%	500	21%	250	47%	360	52.3
45-64 years	17%	1,000	27%	500	40%	360	164.1
≥65 years	18%	800	37%	1,050	44%	300	112.1
<b>Overall</b>	<b>17%</b>	<b>976</b>	<b>26%</b>	<b>783</b>	<b>43%</b>	<b>352</b>	<b>505.6</b>

Source: Primary data collected through the MS Impact Survey, combined with the published MS prevalence estimates. Transportation costs include medical tourism.

### ***Medical Services Not Covered by Insurance***

More than one third of MS Impact Survey respondents indicated that they had expenses either for alternative, non-traditional, or experimental treatments that were not covered by insurance and were paid for out-of-pocket. **Exhibit III-14** shows the percentage of persons with MS who

incurred medical expenses for such treatments, median expenditures, and the total expenditures by age and gender. Overall, persons with MS and their families spent more than \$342 million.

**Exhibit III-14. Estimated medical costs due to MS not covered by insurance**

	Medical expenses on alternative and non-traditional treatments		Total Cost (in Million \$s)
	% of Persons with MS with the Expense	Median Cost (\$)	
<b>Males</b>	<b>39%</b>	<b>1,000</b>	<b>95.5</b>
18-44 years	38%	1,000	26.4
45-64 years	37%	1,200	54.7
≥65 years	26%	1,000	14.4
<b>Females</b>	<b>42%</b>	<b>900</b>	<b>246.9</b>
18-44 years	46%	1,000	85.8
45-64 years	37%	950	127.4
≥65 years	26%	778	33.7
<b>Overall</b>	<b>36%</b>	<b>1,000</b>	<b>342.4</b>

Source: Primary data collected through the MS Impact Survey, combined with the published MS prevalence estimates. Transportation costs include medical tourism.

***Disability Income***

As shown in **Exhibit III-15**, around 6% of the persons with MS received Supplemental Security Income (SSI), 26% of the persons with MS received Social Security Disability Insurance (SSDI), and 22% other types of disability income (OTDI). Persons with MS younger than age 65 are more likely to receive SSDI and OTDI. The overall disability income, although considered a type of transfer cost, is substantial and totals \$6.5 billion, with the 45-64 year age group receiving the largest share of the total disability income.

**Exhibit III-15. Estimated disability income received by persons with MS in 2019**

	% with SSI in Past 12 Month	Median SSI among those with SSI (\$)	% with SSDI in Past 12 Month	Median SSDI among those with SSDI (\$)	% with OTDI* in Past 12 Month	Median OTDI among those with OTDI (\$)	Total Disability Income (in Million \$s)
<b>Males</b>	<b>9%</b>	<b>2,000</b>	<b>29%</b>	<b>18,000</b>	<b>30%</b>	<b>8,750</b>	<b>2,089.1</b>
18-44 years	3%	402	17%	14,300	17%	4,600	218.1
45-64 years	9%	3,523	38%	19,800	27%	9,200	1,269.9
≥65 years	15%	2,200	22%	14,886	51%	14,000	601.1
<b>Females</b>	<b>4%</b>	<b>10,000</b>	<b>26%</b>	<b>15,000</b>	<b>19%</b>	<b>11,000</b>	<b>4,424.8</b>
18-44 years	4%	3,000	16%	13,380	8%	4,000	469.8
45-64 years	2%	2,000	35%	15,000	21%	9,722	2,625.7
≥65 years	9%	12,600	18%	15,300	30%	13,000	1,329.3
<b>Overall</b>	<b>6%</b>	<b>5,443</b>	<b>26%</b>	<b>15,690</b>	<b>22%</b>	<b>10,325</b>	<b>6,514.0</b>

Source: Primary data collected through the MS Impact Survey, combined with the published MS prevalence estimates. \*Annual other types of disability income (OTDI).

### E. Total Economic Burden of MS in 2019

The total economic burden of MS in the U.S. in 2019 was \$85.4 billion, of which slightly more than 70% were direct medical costs. As shown in **Exhibit III-16**, MS is associated with a total excess medical cost of \$63.3 billion in 2019 and an average excess cost of \$65,612. Because the majority of people with MS are younger than 65, the age groups younger than 65 cumulatively represent slightly less than 80% of the total medical cost of MS. Males, although incurring slightly higher per-person cost than females with MS, did have a lower overall direct medical cost burden, because there are fewer males with MS. Beside the prescription medication related costs that include cost of DMT, outpatient medication and administration and other outpatient care (including outpatient facilities and other ancillary care) are the three largest cost categories. Per-person cost of outpatient medication and administration is \$8,049 and \$5,737 for other outpatient care.



**Exhibit III-16. The direct medical cost of MS in 2019 by types of services and population characteristics**

	Total Excess Medical Cost due to MS		Per Person (\$)
	(in Million \$s)	Percentage of the Total	
<b>Age</b>			
18-44	\$16,554	26.2%	\$64,705
45-64	\$32,512	51.5%	\$67,230
≥65	\$14,117	22.3%	\$62,535
<b>Gender</b>			
Male	\$17,439	27.6%	\$70,608
Female	\$45,744	72.4%	\$63,693
<b>Type 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	\$6,750	10.7%	\$6,994
Other outpatient facilities	\$5,537	8.8%	\$5,737
Physician office	\$4,636	7.3%	\$4,803
Durable medical equipment	\$252	0.4%	\$262
Physician office prescription	\$1,018	1.6%	\$1,055
Other ancillary	\$1,728	2.7%	\$1,790
Prescription medication without DMT	\$3,99	6.1%	\$4,143
Prescription medication DMT	\$33,930	53.7%	\$35,154
<b>Overall</b>	<b>\$63,328</b>	<b>100%</b>	<b>\$65,612</b>

Source: Lewin analyses of MS prevalence combined with direct medical cost estimates using 2017-2019 Optum claims, 2017-2019 Medicare Standard Analytical File 5% sample claims, and 2018 Medicare Current Beneficiary Survey (MCBS). DMT: Disease-modifying therapies.

The estimated total indirect and non-medical costs of MS was \$22.1 billion in 2019, with a little less than \$17.9 billion for persons with MS and another \$4.2 billion for unpaid caregivers. Among the \$22.1 billion, total indirect cost was \$21.0 billion, non-medical cost \$0.7 billion, and medical costs not covered by insurance \$0.3 billion. Future earnings loss due to MS related premature death, losses due to presenteeism, and absenteeism are the three largest indirect cost categories for persons with MS. The cost of acquiring daily non-medical care and special equipment for home or vehicle represent the largest non-medical costs. Productivity loss due to absenteeism and presentism among the caregivers was about half of the productivity losses to persons with MS. Average per-person indirect and non-medical costs were \$29,269 (persons with MS and caregiver losses combined), with \$21,741 due to indirect cost, \$780 due to non-medical costs, and \$355 due to medical costs not covered by insurance. (Exhibit III-17).

**Exhibit III-17. The indirect and non-medical costs of MS in 2019 by cost component**

	Total Indirect and Medical Costs (in Million \$s)			Per Person (\$)		
	Persons with MS Loss	Caregivers Loss	Persons with MS, Caregivers	Persons with MS Loss	Caregive rs Loss	Personswit h MS, Caregivers
<b>Indirect costs</b>	<b>16,801</b>	<b>4,183</b>	<b>20,984</b>	<b>17,407</b>	<b>4,333</b>	<b>21,741</b>
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
<b>Non-medical costs</b>	<b>752</b>	<b>NA</b>	<b>752</b>	<b>780</b>	<b>NA</b>	<b>780</b>
Paid daily non-medical care	247	NA	247	256	NA	256
Home modification	159	NA	159	165	NA	165
Special equipment at home/on a vehicle	202	NA	202	209	NA	209
Transport expenses	144	NA	144	150	NA	150
<b>Healthcare services not covered by insurance</b>	<b>342</b>	<b>NA</b>	<b>342</b>	<b>355</b>	<b>NA</b>	<b>355</b>
Alternative, non-traditional and experimental treatments	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 MS Impact Survey data, supplemented with other data sources such as CDC Wonder death records, Bureau of Labor Statistics earnings data; combined with the published prevalence estimates for 2019, and Census population projection for 2019.

An additional \$6.7 billion were transfer payments due to disability income or other financial assistance received by persons with MS (**Exhibit III-18**). SSDI accounts for the largest proportion of the disability income cost component (60%).

**Exhibit III-18. Transfer payments associated with MS to the persons with MS in 2019**

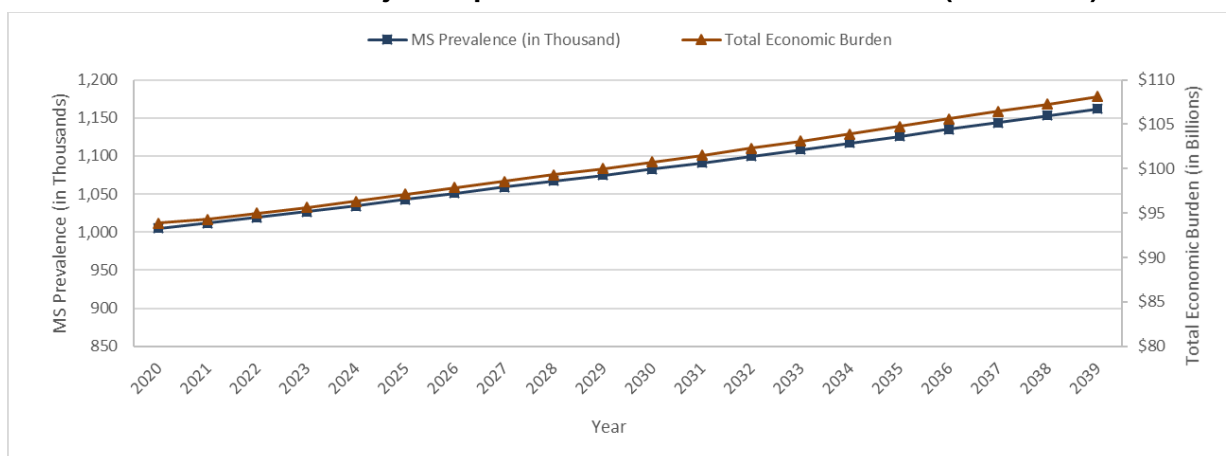
	Total Transfer Costs (in Million \$s)	Per Person (\$)
<b>Disability income</b>		
Financial assistance from charitable organizations	178	184
Supplemental Security Income (SSI)	290	301
Social Security Disability Insurance (SSDI)	4,026	4,171
Other disability income	2,198	2,277
<b>Overall</b>	<b>6,692</b>	<b>6,933</b>

Source: Lewin analyses of MS Impact Survey data, supplemented with other data sources such as CDC Wonder death records, Bureau of Labor Statistics earnings data; combined with the published prevalence estimates for 2019, and Census population projection for 2019.

## IV. Projections 2020-2039

In addition to estimating the economic burden of MS in 2019, we also projected the future prevalence and burden of MS for the next twenty years. Specifically, we applied the estimated age and gender specific MS prevalence rate in 2019 to U.S. Census population projections for years 2020-2039. The projected MS prevalence based on this approach factors in population growth and demographic changes. Next, we also assumed that current MS incidence increases at annual 2.3% and mortality rates remain constant during this period. Combining the projected future MS prevalence with the estimated 2019 per-patient burden by cost component, we projected the future overall impact of MS until 2039. This approach also assumes that per-person burden remains the same over time, which may not be true given changes in the costs of medical treatments. **Exhibit IV-1** summarizes our projections.

**Exhibit IV-1. Projected prevalence and burden 2020-2039 (in 2019 \$s)**

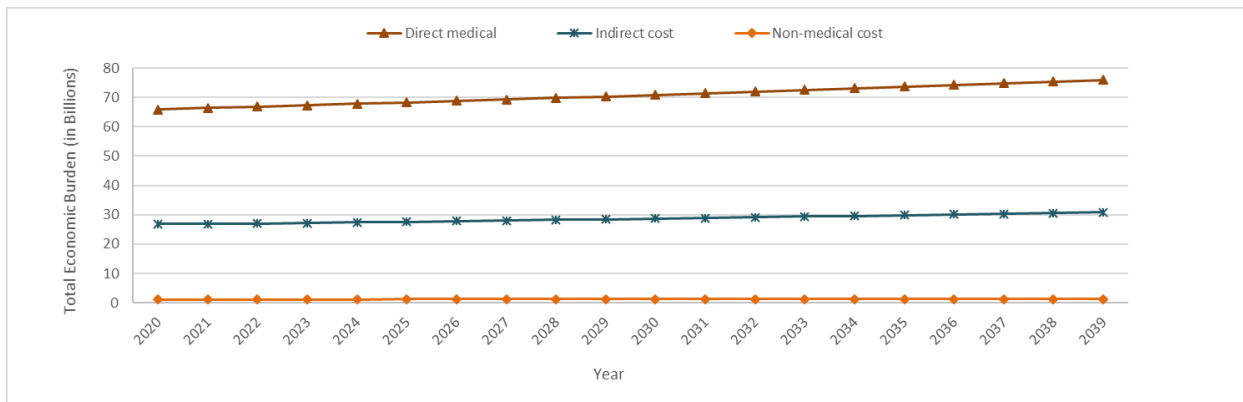


Source: Lewin analyses.

By 2039, the prevalence of MS in the U.S. is projected to increase to 1.2 million people and the economic burden will increase to \$108.1 billion (from \$85.3 billion in 2019).

**Exhibit IV-2** shows the burden projections by cost components: direct medical costs, indirect costs (i.e., labor market and social productivity losses), and non-medical costs (the latter also includes costs for healthcare services not covered by insurance). The medical direct costs are projected to increase to \$76.0 billion by 2039 (a 20% change from \$63.3 billion in 2019). The change in indirect cost is equally drastic: from \$21.0 billion in 2019 to \$30.8 billion in 2039, representing a 47% increase.

**Exhibit IV-2. Projected direct, indirect, and non-medical costs 2020-2039 (in 2019 \$s)**



Source: Lewin analyses.

## V. Discussion

This new study provides a comprehensive assessment and a deeper understanding of the economic burden of MS in the U.S. in 2019. The total economic burden of MS was \$85.4 billion in 2019, including a direct medical cost of \$63.3 billion (or 74% of the total burden) and nearly \$22.1 billion in indirect costs, non-medical costs, and medical costs for treatments not covered by insurance. Additionally, the burden is even higher if the government supplemental income programs based on disability eligibility are taken into account. Transfer payments to persons with MS, whose ability to participate in the labor market is significantly affected by MS, represent an additional \$6.7 billion. These findings show that the true impact of MS has been underestimated in the literature.<sup>11,12</sup>

Another highlight of the study is the Economic Impact of Multiple Sclerosis Survey. This primary survey was specifically designed and administered for this study to deepen the understanding of the full spectrum of the economic impact of MS. The survey was able to collect detailed data on a broad set of indirect and non-medical costs of MS that were previously unavailable, especially the impact of MS on unpaid caregivers. This survey is one of the largest surveys conducted so far and received near 1,000 responses from the MS community.

### Findings and Discussion of the Economic Burden of MS in 2019

**Prevalence:** Based on an analysis of the 2010 prevalence rates by gender and age group in Wallin et al (2019), we found about 1.0 million individuals in the U.S. with diagnosed MS in 2019. MS is much more prevalent in the 45-74 population than in the younger population or the 75 and older population. More females than males have MS: the MS prevalence rate is almost three times higher among females than among males.

**Direct medical cost:** MS is associated with an excess medical cost of \$63.3 billion in 2019, higher than previous U.S. based estimates. The vast majority of the medical cost of MS is borne by commercially insured populations younger than 65 years (about 80%); the remaining 20% are for Medicare populations age 65 and older. Average per-person cost was \$65,612 (\$66,356 for persons with MS and <65 years of age, and \$63,175 for those age ≥65). Per-person costs are lower if the cost for DMT (the largest cost driver) is excluded: \$29,258 for those <65 years and \$34,392 for

those age 65 and older. While prescription medication cost (including DMT and non-DMT retail prescription drugs) is the largest cost driver (nearly 60% of medical costs or \$37.9 billion), outpatient medication and costs associated with outpatient facilities represent the next two costly types of service (\$6.7 billion and \$5.5 billion, respectively).

One consideration to note about the excess cost of non-acute institutional care due to MS is that although Medicare does not cover the cost of nursing home care or longer SNF stays, the MCBS captures all medical expenses paid by Medicare, patient out-of-pocket payments, and payments by other payers for Medicare beneficiaries. Therefore, the direct medical costs estimated for the Medicare population in this study should be interpreted as the MS cost paid by all possible sources for those who are eligible for Medicare, not only those paid by the Medicare program.

**Indirect and non-medical costs:** The estimated total indirect and non-medical cost of MS is \$22.1 billion in 2019, with nearly \$17.9 billion to persons with MS and another \$4.2 billion to unpaid caregivers. Average indirect and non-medical cost per person with MS is \$18,542 for persons with MS only and \$22,875 for persons with MS combined with caregiver burden. Total indirect cost (persons with MS and caregiver combined) is \$22.1 billion with costs associated with premature death being the largest share (36%), followed by presenteeism cost (27%), and absenteeism costs (25%). Total non-medical cost is \$0.7 billion with the paid non-medical daily care being the largest share, followed by purchase of special equipment for home or vehicle. Finally, medical costs associated with experimental, alternative, and non-traditional treatments, which are not covered by insurance, represent \$0.3 billion. Additionally, MS-associated disability income, including SSI, SSDI, and other disability income, is approximately \$6.7 billion, although this is considered transfer costs and excluded from the overall burden estimate.

### **Comparison with other MS burden estimates and cost of other neurologic diseases in the literature:**

The total economic burden of MS estimated in this study are higher than previous U.S. based studies of MS burden. For example, based on the 1994 data, the total annual cost of MS was estimated at \$34,103 per person.<sup>11</sup> A more recent study in 2006 estimated that the average cost of MS was about \$47,215 per-patient per-year (2004 dollars).<sup>12</sup> Our direct medical cost per person with MS of \$65,612 is substantially higher than in these previous studies even when those cost estimates are inflated to 2019 dollars. The largest cost component of our medical costs is DMT that are not included in Whetten-Goldstein et al (1998). For example, their excess cost estimate for services including hospital, nursing home, physicians, other health services, prescription drugs, and formal care was close to \$6,000 in 1994 dollars or above \$10,000 in 2019 dollars. If one would add the DMT cost to per person Whetten-Goldstein et al's estimate, it will be over \$60,000. A more recent study by Dieleman et al (2020), estimated medical costs of MS to be \$13.9 billion (95% confidence interval: \$12.6-\$15.6 billion) in 2016 dollars.<sup>26</sup> Even when adjusted for inflation, this estimate is substantially smaller than the direct medical costs estimated in this study (\$63.3 billion). However, these studies have significantly different data sources, methods, and include different cost. Therefore, any comparison between the findings of this new study and any previous literature should consider these differences.

The total (direct and indirect) cost estimates from our study are similar to some other chronic, disabling diseases in the U.S. An earlier Lewin study for the Muscular Dystrophy Association

found a per-capita cost (including direct medical, non-medical, and indirect costs) estimate of \$63,693 for amyotrophic lateral sclerosis (ALS) and \$50,952 for Duchenne muscular dystrophy (DMD) in 2010 dollar value.<sup>27</sup> While per-person burden of Parkinson's disease is slightly smaller than per-person burden of MS (\$49,997 in 2017 dollars), the indirect and non-medical costs of Parkinson's are slightly higher than the indirect, non-medical, and costs healthcare services for MS not covered by insurance (\$25,558 in 2017 dollars vs \$22,875 in 2019 dollars).<sup>28</sup>

## Study Limitations

A key limitation of the study is the use of MCBS data to obtain cost estimates of long-term care costs and prescription drug costs for the Medicare population, as this data was not available in the Medicare 5% claims data. As a result, certain population strata specific analyses (e.g., by race/ethnicity or by fine age groups) in this study encountered the small sample size issue. When sample sizes were too small for valid analysis, we aggregated the analysis to larger subgroups (e.g., <65 and ≥65), to provide more robust cost estimates. However, certain strata-specific estimates may still be subject to small sample size and outlier issues. Additionally, prescription drug data does not account for rebates and discounts, which can be significant depending on the payer, and, hence, might not reflect accurate drug costs.

A second limitation is the lack of MS-specific mortality data among people with MS younger than 65. Relying solely on the CDC WONDER data might underestimate the MS-specific mortality, as MS is not always listed as a cause of death. MS is often listed as a secondary cause of death and the cause of death of persons with MS is often listed as other factors. Therefore, we used Medicare 5% data to estimate mortality rate for adults older than 65 and imputed mortality for those younger than 65. Specifically, we multiplied the WONDER non-MS death rate for each age 18-64 by the calculated MS/non-MS death ratio for each age 18-64 by applying the average change in the ratio (derived by regression analysis) to the ratio for each year from 64 to 18. This approach allowed us to adjust up the potentially underestimated WONDER death rate for people with MS.

A third limitation of the study is that the indirect and non-medical costs were estimated based on a primary survey with self-reported data. Families that responded to the survey may not be a completely representative sample. The MS Impact Survey was administered to a convenience sample rather than a true random sample of the MS population, due to lack of access to the sampling frame (i.e., there is no national database or other source that tracks the entire population with MS which we could accessed and used for sampling). However, the relatively large sample size of the final responses to our survey, the diversity in the sample subject characteristics, and the weighting method used helped to mitigate the potential bias of non-response and non-representativeness. The survey was relatively long, so it might be possible that the families most affected by the disease were less likely to return the survey creating a selection bias. Comparing demographic characteristics of survey respondents to claims data, the survey respondents were slightly younger. To address potential bias in the estimates, we created weights that accounted for demographic differences in the respondent sample and the MS national population, which we applied to the survey responses. As with any other survey research, indirect and non-medical costs estimated based on self-reported data may be subject to recall bias. Additionally, we reviewed the distribution of answers for questions used in the cost calculation and concluded that, with an exception of volunteering hours, distributions of other variables align with our expectations. In our calculations of indirect costs, we took the conservative approach and used medians, rather than averages. Due to reported volunteering hours being



unreasonably high relative to the average national volunteering hours. This could be a result of the recall bias or the social desirability bias (i.e., tendency to overestimate own volunteering hours).<sup>29</sup> We followed the conservative approach and used the national average volunteering hours for a benchmark of volunteering before MS had a significant impact.

A fourth limitation is the exclusion of the US military veteran population that has a unique health care system that includes disability retirement and funding programs for vocational rehabilitation, educational grants and home loans. Costs for both MS specific medications and prosthetic products are lower than the private sector with limited to no co-pays. Including this group of patients with MS would provide a contrast to the relatively high costs of care in the private health care system.

A final limitation of the study is that our projections assume that current MS mortality rates and per-capita burden remain constant during the projection period.

## Conclusion

This new study provides a comprehensive evaluation of the current and future impact of MS in the U.S. by updating cost components that were included in previous studies as well as capturing those that have been omitted in previous research. Using diverse and best available primary and secondary data sources, we estimated the overall economic burden of MS to be nearly \$85.4 billion in 2019, including \$63.3 in direct medical cost and \$22.1 billion in indirect, non-medical, and medical costs not covered by insurance. This estimate is much higher than previously reported due to both a higher prevalence of MS and a higher per-capita cost (per-capita direct medical cost is \$65,612 and indirect and non-medical cost is \$22,875 when persons with MS and caregiver losses are combined). Our findings show that MS significantly affects individuals with the disease, their unpaid caregivers, payers, and employers. Commercial payers bear the largest share of excess medical cost, as most persons with MS are younger than 65 years. Employers experience significant productivity loss from those persons with MS and their caregivers who are active in the labor force.

The findings of this study help underscore the burden of MS in the U.S. and potential impact of policy interventions. The results suggest a possible role for additional policy initiatives to better support individuals and families, in terms of providing treatment and long-term care, work-site support, employment and occupational training. The findings will inform the decision-making in MS related health resource investment and prioritization.

## Appendix A: Cost of Disease-Modifying Therapies

**Exhibit A-1. Percent of people with MS treated with DMT and per capita DMT cost (in 2019)**

Gender	Age	% of people with MS who use DMT	DMT cost	
			Per-user of DMT	Per-person with MS
Female	18-44	47.3%	\$57,202	\$30,561
	45-64	54.9%	\$66,139	\$39,569
	>=65	40.0%	\$79,650	\$31,837
Male	18-44	51.3%	\$61,859	\$36,196
	45-64	54.9%	\$68,240	\$40,301
	>=65	21.1%	\$92,719	\$19,536

Source: Lewin analyses of MS prevalence combined with direct medical cost estimates using 2017-2019 dNHI claims, 2017-2019 Medicare SAF 5% sample claims, and the 2018 Medicare Current Beneficiary Survey (MCBS). DMT: disease-modifying therapies.

## Appendix B: Comparison Group Characteristics

**Exhibit B-1. Comparison of age, gender, & race/ethnicity between MS and comparison groups by data source**

		MS		Comparison	
		N	Percent	N	Percent
<b>dNHI Claims Data</b>					
<b>Total</b>		<b>10,589</b>	<b>100%</b>	<b>105,893</b>	<b>100%</b>
Gender	Male	2,076	19.6	20,763	19.6
	Female	8,513	80.4	85,130	80.4
Age Group	18-44	4,028	38.0	40,283	38.0
	45-64	6,561	52.0	65,610	62.0
	≥65	N/A	N/A	N/A	N/A
Race/Ethnicity	NH White	6,627	62.6	66,270	62.6
	NH Black	969	9.2	9,690	9.2
	Other (including Hispanic)	1,421	13.4	14,207	13.4
	Unknown	1,573	14.9	15,727	14.9
<b>Medicare 5% Claims Data</b>					
<b>Total</b>		<b>5,406</b>	<b>100%</b>	<b>54,060</b>	<b>100%</b>
Gender	Male	1,341	24.8	13,413	24.8
	Female	4,065	75.2	40,647	75.2
Age Group	18-44	662	12.3	6,623	12.3
	45-64	2,321	42.9	23,207	42.9
	≥65	2,423	44.8	24,230	44.8
Race/Ethnicity	NH White	4,535	83.9	45,353	83.9
	NH Black	648	12.0	6,477	12.0
	Other (including Hispanic)	161	3.0	1,613	3.0
	Unknown	62	1.1	617	1.1
<b>Medicare Current Beneficiary Survey (MCBS) Data</b>					
<b>Total</b>		<b>253,585</b>	<b>100%</b>	<b>1,855,913</b>	<b>100%</b>
Gender	Male	78,058	30.8	573,853	30.9
	Female	175,527	69.2	1,282,060	69.1
Age Group	18-64	116,417	45.9	897,199	48.3
	≥65	137,168	54.1	958,714	51.7
Race/Ethnicity	NH White	203,234	80.1	1,457,071	78.5
	NH Black	24,506	9.7	209,881	11.3
	Other (including Hispanic)	25,118	9.9	175,319	9.4
	Unknown	726	0.3	13,642	0.7

Source: Lewin analyses of 2017-2019 Optum claims, 2017-2019 Medicare Standard Analytical File 5% sample claims, and 2018 Medicare Current Beneficiary Survey (MCBS). NH: Non-Hispanic.

**Exhibit B-2. Comparison of per-capita cost between MS and comparison groups, by age, gender, and insurance (in 2019 \$s)**

Insurance	Age Group	Gender	Per-MS (\$)	Per-Comparison Person (\$)
Private	18-44	Male	74,454	3,741
		Female	68,860	6,372
	45-64	Male	80,622	9,108
		Female	75,662	9,877
Medicare	18-64	Male	83,956	12,616
		Female	61,163	11,740
	≥65	Male	78,878	10,373
		Female	69,558	8,994

Source: Lewin analyses of MS prevalence and Census population projection for 2019; combined with direct medical cost estimates using 2017-2019 Optum claims, 2017-2019 Medicare Standard Analytical File 5% sample claims, and 2018 MCBS.

## Appendix C: Comparison of Death Rates

**Exhibit C-1. Comparison of death rates derived from CDC Wonder and Medicare 5% data for the MS and non-MS's elderly population (2018)**

Gender/Age Group	MS Wonder Death Rate	MS Claims Death Rate	Non-MS Wonder Death Rate	Non-MS Claims Death Rate
<b>Males</b>				
65-74	1.73%	6.92%	2.22%	2.30%
75+	4.55%	12.80%	7.52%	7.92%
<b>Females</b>				
65-74	0.98%	5.82%	1.43%	1.49%
75+	6.47%	12.01%	6.72%	7.11%

Source: Lewin analyses of 2015-2017 CDC Wonder and 2018 Medicare 5% claims data.

## Appendix D: Survey Questionnaire “Economic Impact of Multiple Sclerosis: Survey Instrument”

*August 20, 2020*

# Economic Impact of Multiple Sclerosis Survey

Funded by The National Multiple Sclerosis Society

## *Survey Overview*

Multiple Sclerosis can significantly impact people living with the disease and their families both financially and socially. To better understand these impacts, The National Multiple Sclerosis Society (NMSS) has partnered with the Lewin Group to develop this survey. Your answers will help us better understand the economic impact of Multiple Sclerosis. These impacts are important considerations in healthcare decision-making that could affect patients’ access to medicines or other healthcare services. The results of this survey will be used in discussions with policymakers to advocate for policies to improve the lives of people with Multiple Sclerosis and their families.

Please note that participation in this survey is voluntary.

### **You should take this survey if:**

- You or someone in your family has Multiple Sclerosis,
- You are familiar with your family’s finances, and
- You know your family’s Multiple Sclerosis-related health care needs.

**Please fill out only one survey per family.** You can ask family members to help answer questions. You may also find it helpful to have other documents handy when completing this survey, such as your 2019 tax returns, insurance statements, and medical bills.

The survey has a total of 32 questions and should take about thirty-five (35) minutes to complete. You can take the survey any time before [month day, 2020]. Please try your best to answer all of the questions. If you are not sure about a question, your best estimate is fine. Please note:

- There are minimal foreseeable risks or discomforts to the survey participant.
- Survey responses will be anonymous and de-identified per HIPAA requirements and all data will be stored securely.
- Your answers will be included along with answers from other participants and will only be shared with qualified researchers; survey results will only be published as group statistics.
- By completing this survey, you are giving your consent for your de-identified information to be used for research.



The survey is formatted to best fit a computer screen so please complete the survey from a computer if possible. While you can leave in the middle of the survey and return at the place you left off, we highly encourage completing the survey in one sitting. If you do leave the survey before completing it, you can return to where you have left off using the same survey link, computer, and browser. If you have questions about the survey, please email the National Multiple Sclerosis Society team at [MSEconomicImpact@nmss.org](mailto:MS_EconomicImpact@nmss.org).

Please answer this survey based on your typical family situation in calendar year 2019 as we are interested in experiences that reflect a full year. Please DO NOT account for any impact COVID-19 might have had on your situation.

Thank you for taking part in this important survey!

### Section A: Health Status

This section asks about the health of the person in your family with Multiple Sclerosis (MS), including their diagnosis history and current symptoms.

**Please note: If the Person with MS in your family is no longer living, please answer the questions as best you can based on your knowledge of his/her experience with MS during the last year of life.**

**If there is more than one person with MS in the family, please provide answers for the person who has had MS for the longest period of time.**

*Multiple choice, single answer, required*

1. Which of the following **best describes you** (the person who is responding to this survey)?

- A person with MS
- A family caregiver for someone who has MS
- A paid caregiver for someone who has MS
- A family member of someone who has MS, but not a direct caregiver (e.g., family member who is not responsible for organizing/providing day-to-day care)
- A close friend to someone who has MS, but not a caregiver
- Do not have MS, no one in the family had MS, and do not know anyone with MS (*the remainder of the survey is not required*)

*Multiple choice, single answer, required*

2. How many family members in your household have MS?

- One
- Two
- Three
- Four or more

*If answers to Q2 are “Two”, “Three”, or “Four or more”, then display: ‘For the rest of the survey, please answer based on the experience and care needs of the person who has had MS for the longest period of time’*

*Text entry, not required, display only for people who chose options other than “A person with MS” in Q1.*

**Validation:** *logic requires number entry between 1920-2020*

3. If the Person with MS has passed away, please tell us when they passed away. *Please enter in MM YYYY format. For Month, logic requires number entry between 1 and 12; for Year, logic requires number entry between 1920 and 2020. Leave blank if not applicable.*

Month \_\_\_\_\_ Year \_\_\_\_\_

*Text entry, required*

**Validation:** *logic requires number entry between 1920-2020*

4. In which year did the Person with MS begin experiencing their first symptoms of MS? If you do not know the exact year, please provide your best estimate. *Please enter in YYYY format. Logic requires number entry between 1920 and 2020.*

\_\_\_\_\_

*Text entry, required*

**Validation:** *logic requires number entry between 1920-2020*

5. In which year did the Person with MS receive a confirmed diagnosis of MS? If you do not know the exact year, please provide your best estimate. *Please enter in YYYY format. Logic requires number entry between 1920 and 2020.*

\_\_\_\_\_

*Multiple choice, single answer, required*

6. Which of the following best describes the type of MS the Person with MS is/was living with?

- Relapsing-Remitting MS (RRMS)
- Primary-Progressive MS (PPMS)
- Secondary-Progressive MS (SPMS)
- Clinically Isolated Syndrome (CIS)
- Other
- Do not know

*Multiple choice, not required, display only for people who chose option “Other” in Q6*

6a. If the Person with MS was diagnosed with an “Other” subtype not listed in Q6, please provide the subtype below.

\_\_\_\_\_

*Multiple choice, multiple answer, required*

7. Was the Person with MS ever diagnosed with any of the **conditions** below? *Check all that apply.*

- Depression
- Anxiety
- Hypertension (high blood pressure)

- Hyperlipidemia (high cholesterol)
- Fibromyalgia
- Chronic lung disease
- Epilepsy
- Bipolar Disorder
- Irritable bowel syndrome (IBS)
- Inflammatory bowel disease
- Psoriasis
- Ischemic heart disease
- Diabetes
- Gastrointestinal diseases
- Thyroid diseases
- Arthritis
- Other
- None of the above

*Text entry, not required, display only for people who chose option "Other" in Q7.*

7a. If the Person with MS was diagnosed with "Other" condition(s) not listed in Q7, what additional condition(s) does the Person with MS have? Please enter the names of all conditions, separating each condition with a comma (e.g., condition1, condition2).

---

*Matrix table, single answer, required.*

**Validation:** One answer per row.

8. Is the Person with MS limited in his or her ability to complete any of the following activities on a typical day? Please check ONLY ONE answer for each activity.

	Able to do	Some limitations	Significant limitations	Completely unable	Not applicable or do not know
Learning	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Remembering	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Concentrating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Speaking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using a smartphone or a tablet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using a laptop or computer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Eating independently	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bathing or showering	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using the toilet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Getting in or out of bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Getting out of chairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Going up and down the stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Walking independently	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Balancing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Controlling a joystick	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gripping things tightly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Carrying things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pushing a manual wheelchair	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Doing heavy housework	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Doing light housework	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Managing medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Driving a car or van	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Managing money and paying bills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using transport (bus, train)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Preparing meals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in age-appropriate social events with friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Staying home alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Single answer, required.*

9. From the list below, which condition best describes the Person with MS?

- Has mild MS symptoms that do not limit activities of daily living.
- Has mild MS symptoms such as sensory problems, mild bladder problems, mild incoordination or weakness, and fatigue, but there is no significant problem with walking.
- Has significant problems walking, but does not use any type of walking aid.
- Can walk 25 feet without a cane or some other form of support, such as a splint, brace, or crutch but uses them occasionally or for walking longer distances.
- To be able to walk 25 feet, must use a cane or some other form of support on one side such as holding on to furniture or touching the wall.
- To be able to walk 25 feet, must use two canes, a walker, or two crutches.
- The only form of mobility is a wheelchair or a scooter.
- Completely bedridden (unable to sit in a wheelchair for more than an hour).
- Do not know

## Section B: Family Characteristics

This section asks questions about the **demographic information** of the Person with MS and the unpaid caregiver(s) (if applicable), and general background information of the family. If you are unsure about a specific question, please answer to the best of your knowledge.

**Unpaid caregivers (either Primary or Secondary)** provide daily care or assistance to the Person with MS to assist them in managing their disease. They may be family members, other relatives, or friends, and **are not receiving payment for the care they provide**. Unpaid caregivers provide assistance with activities of daily living (ADLs), including eating, bathing, dressing, toileting (being able to get on and off the toilet and perform personal hygiene functions), transferring (being able to get in and out of a bed or a chair), doing household work such as home maintenance or outdoor activities, meal preparation, driving to and from doctors' offices or stores, and providing company.

Please refer to the individual who spends the most time providing unpaid care to the Person with MS as the **Primary Caregiver**. If there is more than one caregiver, please refer to the individual who provides the most unpaid care after the Primary Caregiver as the **Secondary Caregiver**. Please assign each caregiver as Primary or Secondary based on their role at the end of 2019, as we are looking at 2019 experiences.

**As noted above, if the Person with MS in your family is no longer living, please answer the questions as best you can based on your knowledge of his/her experience with MS during the last year of life.**

**If there is more than one person with MS in the family, please provide answers for the person who has had MS for the longest period of time.**

*Multiple choice (drop down menu with full state names), single answer, required*

10. In which state does the Person with MS currently live? Please respond based on where the Person with MS physically resides.

State \_\_\_\_\_

*Matrix table, single answer, required*

***Validation: Only allow individual to respond "Yes" to Secondary Caregiver if they also responded "Yes" to Primary Caregiver.***

11. In 2019, has the Person with MS received care from at least one **unpaid** caregiver (i.e., family members, other relatives, or friends who provided care or assistance to the Person with MS to help them manage their disease)?

	Yes	No
Primary Caregiver (the individual who spent the most time providing <b>unpaid</b> care to the Person with MS)	<input type="checkbox"/>	<input type="checkbox"/>
Secondary Caregiver (the individual who provided <b>unpaid</b> care to the Person with MS, but less frequently than the Primary Caregiver)	<input type="checkbox"/>	<input type="checkbox"/>

*Matrix table, text entry, not required*

**Validation:** Allow numbers between 1920 and 2020

12. What was the **year** of birth for the Person with MS and for each of the unpaid caregiver(s)?  
Please enter in YYYY format. Logic requires number entry between 1920 and 2020.

	<b>Person with MS</b>	<b>Primary Caregiver</b> ( <i>show if the response to “Primary Caregiver” in Q11 was “Yes”</i> )	<b>Secondary Caregiver</b> ( <i>show if the response to “Secondary Caregiver” in Q11 was “Yes”</i> )
<b>Year</b>	_____	_____	_____

*Matrix table, single answer, required*

13. What is the **sex** of the Person with MS and each of the unpaid caregivers(s)?

	<b>Male</b>	<b>Female</b>	<b>Prefer not to answer</b>
Person with MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Primary Caregiver ( <i>show if the response to “Primary Caregiver” in Q11 was “Yes”</i> )	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Secondary Caregiver ( <i>show if the response to “Secondary Caregiver” in Q11 was “Yes”</i> )	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Matrix table, single answer, required*

14. What is the **race** of the Person with MS and each of the unpaid caregiver(s)?

	<b>American Indian or Alaska Native</b>	<b>Asian</b>	<b>Black or African American</b>	<b>Multi-racial</b>	<b>Native Hawaiian or Other Pacific Islander</b>	<b>White or Caucasian</b>	<b>Other</b>	<b>Prefer not to answer</b>
Person with MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Primary Caregiver ( <i>show if the response to “Primary Caregiver” in Q11 was “Yes”</i> )	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Secondary Caregiver ( <i>show if the response to “Secondary Caregiver” in</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	American Indian or Alaska Native	Asian	Black or African American	Multi-racial	Native Hawaiian or Other Pacific Islander	White or Caucasian	Other	Prefer not to answer
<i>Q11 was "Yes")</i>								

*Matrix table, single answer, required*

15. What is the **ethnicity** of the Person with MS and each of the unpaid caregiver(s)?

	Hispanic/Latino	Not-Hispanic/Latino	Prefer not to answer
Person with MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Primary Caregiver ( <i>show if the response to "Primary Caregiver" in Q11 was "Yes")</i> )	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Secondary Caregiver ( <i>show if the response to "Secondary Caregiver" in Q11 was "Yes")</i> )	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



*Matrix table, single answer, required*

16. What is the **highest level of education** attained by the Person with MS and each of the unpaid caregiver(s)? If the person is age 1-17, please choose “Not applicable”. Please scroll to the right to see all answer options.

	<b>Less than a high school diploma</b>	<b>High school diploma (GED or equivalent)</b>	<b>Some College (1-4 years, no degree)</b>	<b>Associate’s Degree (AS, AAS, etc.)</b>	<b>Bachelor’s Degree (BA, BS, etc.)</b>	<b>Master’s Degree (MA, MS, etc.)</b>	<b>PhD or Professional School Degree (MD, JD, etc.)</b>	<b>Prefer not to answer</b>	<b>Not applicable</b>	<b>Do not know</b>
Person with MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Primary Caregiver <i>(show if the response to “Primary Caregiver” in Q11 was “Yes”)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Secondary Caregiver <i>(show if the response to “Secondary Caregiver” in Q11 was “Yes”)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Matrix table, single answer, required*

17. What is the **marital status** of the Person with MS and each of the unpaid caregiver(s)? If the person is age 1-17, please choose “Not applicable”. Please scroll to the right to see all answer options.

	<b>Married</b>	<b>Unmarried but living with partner</b>	<b>Widowed</b>	<b>Divorced/ Separated</b>	<b>Single, Never Married</b>	<b>Prefer not to answer</b>	<b>Not Applicable</b>	<b>Do not know</b>
Person with MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Primary Caregiver ( <i>show if the response to “Primary Caregiver” in Q11 was “Yes”</i> )	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Secondary Caregiver ( <i>show if the response to “Secondary Caregiver” in Q11 was “Yes”</i> )	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Matrix table, single answer, required*

18. What were the **total earnings** of the Person with MS, each of the unpaid caregiver(s), and the entire household of the Person with MS in 2019? Please select the appropriate response category for each person in the table below.

Note: This includes the amount received through wages, salary, commissions, overtime pay, or tips from all jobs before taxes or other deductions, and **EXCLUDES any social security income, supplemental security income (SSI), social security disability insurance (SSDI), or income from savings accounts or other investments. We recommend that you refer to your 2019 tax return.** The **household** includes all family members living with the Person with MS, and excludes co-residents who are financially independent and caregivers who do not live in the same household. **Note that this question asks about earnings in 2019, before the COVID-19 outbreak.**

	<b>Less than \$1,000</b>	<b>\$1,000 to less than \$25,000</b>	<b>\$25,000 to less than \$50,000</b>	<b>\$50,000 to less than \$75,000</b>	<b>\$75,000 to less than \$100,000</b>	<b>\$100,000 to less than \$125,000</b>	<b>\$125,000 to less than \$150,000</b>	<b>\$150,000 to less than \$175,000</b>	<b>\$175,000 to less than \$200,000</b>	<b>More than \$200,000</b>	<b>Prefer not to answer</b>
Person with MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Primary Caregiver <i>(show if the response to "Primary Caregiver" in Q11 was "Yes")</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Secondary Caregiver <i>(show if the response to "Secondary Caregiver" in Q11 was "Yes")</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Entire Household of the Person with MS (do not include any unpaid caregivers if they do not live in the same household)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Matrix table, text entry, required*

*Validation: In number format only (decimals allowed; response can be \$0)*

19. In 2019, how much financial assistance or disability income did the Person with MS receive? If the Person with MS was not eligible or did not receive any of the following, please enter 0.

	<b>Total Amount In 2019 (\$ Before Tax)</b> (If the Person with MS was not eligible or did not receive any of the following, please enter 0.)
Financial assistance received from charitable organizations or other assistance programs (does not include goods or services, monetary contributions only)	_____
<b>Supplemental Security Income (SSI)</b> is a federal program that provides cash payments to those who have limited income and who are blind, disabled, or 65 years or older. This payment is not based on the Person with MS’s prior work or a family member's prior work.	_____
<b>Social Security Disability Insurance (SSDI)</b> is a federal program that provides cash payments to workers who have accumulated a sufficient number of work credits and are physically restricted in their ability to be employed because of a notable disability.	_____
Commercial disability insurance	_____
VA benefits/VA disability compensation	_____
State or federal government employee benefits	_____
State disability insurance	_____
Tax deduction for medical expenses	_____
Other	_____

*Text entry, required only if there is a response to Q19 “Other”*

19a. If the Person with MS received “Other” types of financial assistance or disability income as noted in Question 19, please list the type(s) of financial assistance or disability income received.

\_\_\_\_\_

## Section C: Financial Impact of Multiple Sclerosis

This section asks questions about the costs associated with Multiple Sclerosis (MS) that may impact the Person with MS, their caregiver(s), and their family. These financial impacts include family expenses for certain medical services not covered by insurance, or expenses on things such as home modifications (e.g., building a ramp in place of steps to enter/exit home), personal vehicle modifications, increased transportation costs related to seeking care, and any impact MS may have had on employment or social activities. You may refer to additional resources (e.g., transportation receipts for traveling to and from doctor’s appointments, etc.) to provide the most complete information.

**Again, unpaid caregivers (either Primary or Secondary)** provide daily care or assistance to the Person with MS to help them manage their disease (e.g., helping with daily living activities, etc.). They may be family members, other relatives, or friends, **who are not receiving payment for the care they provide.**

Please refer to the individual who spends the most time providing unpaid care to the Person with MS as the **Primary Caregiver**. If there is more than one caregiver, please refer to the individual who provides the most unpaid care after the Primary Caregiver as the **Secondary Caregiver**. Please assign each caregiver as Primary or Secondary based on their role at the end of 2019, as we are looking at 2019 experiences.

**As noted above, if the Person with MS in your family is no longer living, please answer the questions as best you can based on your knowledge of his/her experience with MS during the last year of life.**

**If there is more than one person with MS in the family, please provide answers for the person who has had MS for the longest period of time.**

*Matrix table, single answer, required*

20. What type of **insurance** did the Person with MS use to pay for the majority of his or her medical expenses? Please check the appropriate box for each type of health insurance.

	Individual Coverage	Family Coverage	No Coverage
Commercial insurance through own employer or legal guardian’s employer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Individual commercial insurance (Private)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Individual coverage purchased via the Affordable Care Act (ACA)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicaid/SCHIP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicare Part A (Hospital Insurance)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicare Part B (Medical Insurance)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicare Part C (Medicare Supplemental Insurance, e.g., Medigap)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicare Part D (Prescription Drug Coverage)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medicare Advantage Plan (Medicare Managed Plans)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Military/CHAMPUS/TRICARE/CHAMPVA or other VA health care program	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Text entry, required only if there is a response to Q20 “Other”*

20a. If the answer to Question 20 was “Other”, please list the type(s) of health insurance coverage that paid for the majority of the medical expenses for the Person with MS in 2019.

\_\_\_\_\_

*Matrix table, single answer, required*

20b. Does the Person with MS have insurance coverage for the below? Please check the appropriate box for each type of coverage.

	<b>Individual Coverage</b>	<b>Family Coverage</b>	<b>No Coverage</b>
Prescription drug coverage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mental health coverage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dental coverage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vision coverage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Text entry, required*

**Validation:** Allow only number format (decimals allowed; response can be \$0)

21. The following healthcare-related services/treatments may not be covered by health insurance. If you utilized any of these services/treatments below in 2019, please provide how much you spent (or your best estimate) in the table below. Please enter 0 in the text box if no money was spent.

		<b>Amount (\$) Spent by Household in 2019 (not spent by insurance or charitable organization)</b> (Please enter 0 in the text box if no money was spent)
a.	Medical cannabis for MS-related symptoms	_____
b.	Experimental treatments (e.g., Hematopoietic Stem Cell therapy (HSCT)) related to MS	_____
c.	Alternative or non-traditional treatments (alternative therapies, massage therapy, acupuncture) related to MS	_____
d.	Mental health treatments or counseling	_____

*Text entry, required*

**Validation:** Allow only number format (decimals allowed; response can be \$0)

22. In 2019, approximately how much was spent on facility/institutional care for the Person with MS by his or her household (**not by an insurance company or charitable organization**)? Please provide your best estimate in the table below. Please enter 0 in the text box if no money was spent.

	<b>Amount (\$) Spent by Household in 2019 (not spent by insurance or charitable organization)</b> (Please enter 0 in the text box if no money was spent)

Adult day care program or facility	_____
Inpatient or outpatient rehabilitation program or facility care	_____
Hospice or palliative care in an inpatient facility	_____
Long-term care facility	_____
Short-term care facility	_____

*Text entry, required*

**Validation:** Allow only number format (decimals allowed; response can be \$0)

23. In 2019, how much was spent on the following expenses for the Person with MS by his or her household (**not by the insurance company or charitable organization**)? Please provide your best estimate in the table below. Please enter 0 in the text box if no money was spent.

		<b>Amount (\$) Spent by Household in 2019 (not spent by insurance or charitable organization)</b> (Please enter 0 in the text box if no money was spent)
a.	<b>Expenses related to purchasing/installing/modifying special equipment at home or on a personal family vehicle</b> (e.g., bathroom equipment such as a shower chair, commode chair, hydraulic commode lift, modification to the wheelchair such as elevated leg rests, modified joysticks and switches, automated/raised desk trays, vehicle modifications to accommodate driver or passenger with disability, etc.)	_____
b.	<b>Expenses on home modifications</b> (e.g., ramps, barrier free lift systems, stair lifts, automatic door openers, technology to enable access through X-box or iPad, other)	_____
c.	Expenses related to <b>hiring someone</b> , including the costs of the hiring process and payments made to professionals, relatives, or friends for providing MS-related daily care to the Person with MS.	_____
d.	Increased <b>transportation costs</b> due to MS (e.g., transportation to and from clinics, specialized facilities, attending clinical trial visits and related parking, etc.)  <i>For example, drives an extra 20 miles per month (240 miles per year) for appointments. This is equivalent to approximately one tank of gas at about \$30 a tank; the resulting amount is \$30 per month (\$360 per year).</i>	_____
e.	Transportation/travel expenses associated with medical tourism (i.e., travel out of country for treatment)	_____

*Matrix table, text entry, required*



**Validation:** logic requires number entry between 1920-2020

24. In which year did each of the unpaid caregiver(s) start providing care to the Person with MS?  
Please enter in an YYYY format. Logic requires number entry between 1920 and 2020.

	<b>Year first began to provide care and assistance to the Person with MS</b>
Primary Caregiver <i>(show if the response to "Primary Caregiver" in Q11 was "Yes")</i>	_____
Secondary Caregiver <i>(show if the response to "Secondary Caregiver" in Q11 was "Yes")</i>	_____

*Matrix table, single answer, required*

25. What was the **job status** of the Person with MS and each of the unpaid caregiver(s) in December 2019?

	<b>Employed full-time</b>	<b>Employed part-time</b>	<b>Not employed, but seeking work (unemployed)</b>	<b>Not employed, but in school</b>	<b>Not employed, not seeking work and not in school</b>	<b>Retired</b>	<b>Not applicable</b>
Person with MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Primary Caregiver ( <i>show if the response to "Primary Caregiver" in Q11 was "Yes"</i> )	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Secondary Caregiver ( <i>show if the response to "Secondary Caregiver" in Q11 was "Yes"</i> )	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Matrix table, single answer, only required if the Person with MS, primary caregiver, or secondary caregiver answered “Employed part-time”, “Not employed, but seeking work,” “Not employed, not seeking work and not in school” or “Retired” to Q25*

26. In December 2019, if the Person with MS or unpaid caregiver(s) was working part-time, no longer working or retired, did MS play a major role in his/her decision to move to part-time work or stop working?

	<b>Yes, MS played a role</b>	<b>No, MS did not play a role</b>
Person with MS <i>(only required if Person with MS answered “Employed part-time”, “Not employed, but seeking work,” “Not employed, not seeking work and not in school” or “Retired” to Q25)</i>	<input type="checkbox"/>	<input type="checkbox"/>
Primary Caregiver <i>(only required if Primary Caregiver answered “Employed part-time”, “Not employed, but seeking work,” “Not employed, not seeking work and not in school” or “Retired” to Q25)</i>	<input type="checkbox"/>	<input type="checkbox"/>
Secondary Caregiver <i>(only required if Secondary Caregiver answered “Employed part-time”, “Not employed, but seeking work,” “Not employed, not seeking work and not in school” or “Retired” to Q25)</i>	<input type="checkbox"/>	<input type="checkbox"/>

*Matrix table, text entry, only required if Person with MS answered “Employed part-time”, “Not employed, but seeking work,” “Not employed, not seeking work and not in school” or “Retired” to Q25*

26a. If the Person with MS was working part-time, was no longer working, or was retired in December 2019, **in which year did he or she move to part-time work, become unemployed or retired/stopped working?** Please enter in an YYYY format. Logic requires number entry between 1920 and 2020.

	<b>Year moved to part-time work</b> <i>(logic requires number entry between 1920-2020) (only appears if Person with MS answered “Employed part-time” to Q25)</i>	<b>Year became unemployed</b> <i>(logic requires number entry between 1920-2020) (only appears if Person with MS answered “Not employed, but seeking work” to Q25)</i>	<b>Year retired or stopped working</b> <i>(logic requires number entry between 1920-2020) (only appears if Person with MS answered “Not employed, not seeking work and not in school” or “Retired” to Q25)</i>
Person with MS	_____	_____	_____

*Matrix table, text entry, required only if Primary Caregiver answered “Employed part-time”, “Not employed, but seeking work,” “Not employed, not seeking work and not in school” or “Retired” to Q25.*

26b. If the Primary Caregiver was working part-time, was no longer working, or was retired in December 2019, **in which year did he or she move to part-time work, become unemployed or retired/stopped working?** Please enter in an YYYY format. Logic requires number entry between 1920 and 2020.

	<b>Year moved to part-time work</b> (logic requires number entry between 1920-2020) <i>(only appears if Primary Caregiver answered “Employed part-time” to Q25)</i>	<b>Year became unemployed</b> (logic requires number entry between 1920-2020) <i>(only appears if Primary Caregiver answered “Not employed, but seeking work” to Q25)</i>	<b>Year retired or stopped working</b> (logic requires number entry between 1920-2020) <i>(only appears if Primary Caregiver answered “Not employed, not seeking work and not in school” or “Retired” to Q25)</i>
Primary Caregiver <i>(show if the response to “Primary Caregiver” in Q11 was “Yes”)</i>	_____	_____	_____

*Matrix table, text entry, required only if the Secondary Caregiver answered “Employed part-time”, “Not employed, but seeking work,” “Not employed, not seeking work and not in school” or “Retired” to Q25.*

26c. If the Secondary Caregiver was working part-time, was no longer working, or was retired in December 2019, **in which year did he or she move to part-time work, become unemployed or retired/stopped working?** Please enter in an YYYY format. Logic requires number entry between 1920 and 2020.

	<b>Year moved to part-time work</b> (logic requires number entry between 1920-2020) <i>(only appears if Secondary Caregiver answered “Employed part-time” to Q25)</i>	<b>Year became unemployed</b> (logic requires number entry between 1920-2020) <i>(only appears if Secondary Caregiver answered “Not employed, but seeking work” to Q25)</i>	<b>Year retired or stopped working</b> (logic requires number entry between 1920-2020) <i>(only appears if Secondary Caregiver answered “Not employed, not seeking work and not in school” or “Retired” to Q25)</i>
Secondary Caregiver <i>(show if the response to “Secondary Caregiver” in Q11 was “Yes”)</i>	_____	_____	_____

*Matrix table, text entry, only required if the Person with MS, Primary Caregiver, or Secondary Caregiver answered “Employed full-time” or “Employed part-time” to Q25*

**Validation:** In number format only, decimals allowed. Logic requires number entry between 0-168

27. If the Person with MS and the unpaid caregiver(s) were employed in December 2019, how many hours was each individual usually working in a typical week?

	<b>Person with MS</b> <i>(only required if Person with MS answered “Employed full-time” or “Employed part-time” to Q25)</i>	<b>Primary Caregiver</b> <i>(only required if Primary Caregiver answered “Employed full-time” or “Employed part-time” to Q25)</i>	<b>Secondary Caregiver</b> <i>(only required if Secondary Caregiver answered “Employed full-time” or “Employed part-time” to Q25)</i>
Hours worked in a typical week in 2019	_____	_____	_____

*Matrix table, text entry, only required if the Person with MS, Primary Caregiver, or Secondary Caregiver answered “Employed full-time” or “Employed part-time” to Q25*

**Validation:** Allow number between 0 – 12 (decimals allowed)

28. In 2019, **how many months was each of the following individuals employed** (full or part-time)? Note: Include any time the person worked or was on paid vacation, paid sick leave, jury duty, or military service.

	<b>Person with MS</b> <i>(only required if Person with MS answered “Employed full-time” or “Employed part-time” to Q25)</i>	<b>Primary Caregiver</b> <i>(only required if Primary Caregiver answered “Employed full-time” or “Employed part-time” to Q25)</i>	<b>Secondary Caregiver</b> <i>(only required if Secondary Caregiver answered “Employed full-time” or “Employed part-time” to Q25)</i>
Months employed in 2019	_____	_____	_____

*Text entry, required; however, if the response to the Person with MS, Primary and Secondary Caregiver’s months employed in Q28 was “0” this question should be skipped.*

**Validation:** Number between 0 – 31, decimals allowed

29. In an average working month in 2019, about how many whole days did the Person with MS or the unpaid caregiver(s) miss work at a job or business, due to the impact of his/her MS or related caregiving responsibilities? Note: Please round down if you missed less than half a day and round up if you missed more than half a day.

	Days missed from work in an average working month (include days when individual was late or left work early) (Maximum of 31 days)
Person with MS <i>(required if the response to the Person with MS’s months employed in Q28 exceeds “0”)</i>	_____

Primary Caregiver <i>(required if the response to the Primary Caregiver’s months employed in Q28 exceeds “0”)</i>	_____
Secondary Caregiver <i>(required if the response to the Secondary Caregiver’s months employed in Q28 exceeds “0”)</i>	_____

*Matrix table, text entry, required only if the response to the Person with MS, Primary or Secondary Caregiver’s months employed in Q28 exceeds “0”.*

**Validation:** *Days between 0 – 31, decimals not allowed*

30. In an average working month in 2019, on how many days did the Person with MS or the unpaid caregiver(s) feel less productive while at work, due to the impacts of his/her MS or related caregiving responsibilities? Note: Include the number of whole days when you felt less productive.

	Days felt less productive at work in an average working month (include whole days when individual was feeling less productive) (Maximum of 31 days)
Person with MS <i>(required if the response to the Person with MS’s months employed in Q28 exceeds “0”)</i>	_____
Primary Caregiver <i>(required if the response to the Primary Caregiver’s months employed in Q28 exceeds “0”)</i>	_____
Secondary Caregiver <i>(required if the response to the Secondary Caregiver’s months employed in Q28 exceeds “0”)</i>	_____

*Matrix table, single answer, required only if the response to the Person with MS, Primary Caregiver, or Secondary Caregiver’s answer to Q30 “Days felt less productive at work” exceeds 0.*

30a. On the days when the Person with MS or the unpaid caregiver(s) felt less productive because of MS, how much on average was each person’s productivity affected on a scale from 0 to 10, where 0 represents “not at all”, 1-3 “mildly”, 4-6 “moderately”, 7-9 “markedly”, and 10 represents “extremely”? Please scroll to the right to see all answer choices.

	Not at all	Mildly			Moderately			Markedly			Extremely
Person with MS <i>(required if the response to the Person with MS’s ‘Days felt less productive at work’)</i>	0	1	2	3	4	5	6	7	8	9	10

<i>in Q30 exceeds "0")</i>												
Primary Caregiver <i>(required if the response to the Primary Caregiver's 'Days felt less productive at work' in Q30 exceeds "0")</i>	0	1	2	3	4	5	6	7	8	9	10	
Secondary Caregiver <i>(required if the response to the Secondary Caregiver's 'Days felt less productive at work' in Q30 exceeds "0")</i>	0	1	2	3	4	5	6	7	8	9	10	

*Matrix table, multiple answer, not required*

31. Please select whether any of the below has **ever** applied to the Person with MS or their caregiver(s) for reasons related to the individual's MS. *Check all that apply for each individual.*

	Person with MS	Primary Caregiver <i>(show if the response to "Primary Caregiver" in Q11 was "Yes")</i>	Secondary Caregiver <i>(show if the response to "Secondary Caregiver" in Q11 was "Yes")</i>
Not able to attend school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lost educational opportunities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Worked at a job for fewer hours	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Changed work schedule	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Changed to telecommuting for work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Missed opportunities for a better job, promotion, or more comprehensive benefits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Changed occupation or employer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chose not to take a job due to concerns over losing government benefits (such as Medicaid)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chose not to take a job because the current job has better benefits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



	Person with MS	Primary Caregiver <i>(show if the response to “Primary Caregiver” in Q11 was “Yes”)</i>	Secondary Caregiver <i>(show if the response to “Secondary Caregiver” in Q11 was “Yes”)</i>
Chose not to take a job or position because of irregular hours, travel requirements, or other, similar, demands related to MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Had to relocate to be closer to medical specialists/ affected family member/ family support, negatively impacting employment or career growth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
None of the above	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Matrix table, text entry, required*

**Validation:** *Number format, decimals allowed; don't allow numbers greater than 56*

32. Approximately how many hours in a typical week was the Person with MS able to participate in the following volunteering activities, **BEFORE** and **AFTER** MS started having a significant impact? *Note: assume the time one can dedicate to volunteering activities per week is no more than 56 hours (8 hours per day, 7 days a week). Please enter '0' for activities that the person does not engage in.*

		Hours spent by the Person with MS on volunteering <b>BEFORE</b> MS started having a significant impact	Hours spent by the Person with MS on volunteering <b>AFTER</b> MS started having a significant impact
a.	Performing volunteer or charity work	_____	_____
b.	Providing help to family, friends, or neighbors unrelated to personal care or care of the Person with MS	_____	_____
c.	Participating in a political or community-based organization	_____	_____

*Matrix table, text entry, required, display if the response to “Primary Caregiver” in Q11 was “Yes”*

**Validation:** *Number format, decimals allowed; don't allow numbers greater than 56*

32a. Approximately how many hours in a typical week was the Primary Caregiver able to participate in the following volunteering activities, **BEFORE** and **AFTER** MS started having a significant impact? *Note: assume the time one can dedicate to volunteering activities per week is no more than 56 hours (8 hours per day, 7 days a week). Please enter '0' for activities that the person does not engage in.*

		Hours spent by the Primary Caregiver on volunteering <b>BEFORE</b> MS started having a significant impact	Hours spent by the Primary Caregiver on volunteering <b>AFTER</b> MS started having a significant impact
a.	Performing volunteer or charity work	_____	_____
b.	Providing help to family, friends, or neighbors unrelated to personal care or care of the Person with MS	_____	_____
c.	Participating in a political or community-based organization	_____	_____

*Matrix table, text entry, required, display if the response to “Secondary Caregiver” in Q11 was “Yes”*

***Validation:** Number format, decimals allowed; don’t allow numbers greater than 56*

32b. Approximately how many hours in a typical week was the Secondary Caregiver able to participate in the following volunteering activities, **BEFORE** and **AFTER** MS started having a significant impact? *Note: assume the time one can dedicate to volunteering activities per week is no more than 56 hours (8 hours per day, 7 days a week). Please enter ‘0’ for activities that the person does not engage in.*

		Hours spent by the Secondary Caregiver on volunteering <b>BEFORE</b> MS started having a significant impact	Hours spent by the Secondary Caregiver on volunteering <b>AFTER</b> MS started having a significant impact
a.	Performing volunteer or charity work	_____	_____
b.	Providing help to family, friends, or neighbors unrelated to personal care or care of the Person with MS	_____	_____
c.	Participating in a political or community-based organization	_____	_____

**Thank You for Your Participation!!!**

Thank you for completing the Economic Impact of Multiple Sclerosis Survey. Please be assured that we will only share summary results with the multiple sclerosis community. Any personal information will be kept completely confidential.

The information you provided is very important to help us better understand multiple sclerosis and its impact on individuals and families and will be incorporated into a national study of the cost of multiple sclerosis being led by the National Multiple Sclerosis Society. Once published, study findings will be available at <https://www.nationalmssociety.org/>.

## Appendix E: Survey Sample Characteristics

**Exhibit E-1. Education attainment and marital status of the persons with MS and unpaid caregivers**

			Unweighted			Weighted		
			MS	PC	SC	MS	PC	SC
<b>Total</b>			<b>946</b>	<b>506</b>	<b>178</b>	<b>965,184</b>	<b>522,371</b>	<b>179,485</b>
<b>Education</b>	Less than a high school diploma	N	2	14	9	1,888	14,759	8,288
		%	0.2	2.8	5.1	0.2	2.8	4.6
	High school diploma (GED or equivalent)	N	76	89	31	77,162	85,444	33,419
		%	8.0	17.6	17.4	8.0	16.4	18.6
	Some College (1-4 years, no degree)	N	174	86	35	175,931	86,393	33,392
		%	18.4	17.0	19.7	18.2	16.5	18.6
	Associate's Degree (AS, AAS, etc.)	N	103	50	22	108,304	50,960	21,472
		%	10.9	9.9	12.4	11.2	9.8	12.0
	Bachelor's Degree	N	317	140	53	320,389	145,929	55,813
		%	33.5	27.7	29.8	33.2	27.9	31.1
	Master's Degree	N	207	83	11	216,117	87,597	11,679
		%	21.9	16.4	6.2	22.4	16.8	6.5
	PhD or Professional School Degree	N	63	39	5	61,690	46,302	4,376
		%	6.7	7.7	2.8	6.4	8.9	2.4
Not Applicable	N	2	3	8	1,753	2,697	7,675	
	%	0.2	0.6	4.5	0.2	0.5	4.3	
Prefer not to answer / Do not know	N	2	2	4	1,949	2,289	3,371	
	%	0.2	0.4	2.2	0.2	0.4	1.9	
<b>Marital Status</b>	Married	N	616	405	65	634,103	419,878	64,309
		%	65.1	80.0	36.5	65.7	80.4	35.8
	Unmarried, but Living With Partner	N	62	39	9	59,026	37,873	9,146
		%	6.6	7.7	5.1	6.1	7.3	5.1
	Widowed	N	21	7	8	23,976	8,496	8,354
		%	2.2	1.4	4.5	2.5	1.6	4.7
	Divorced/ Separated	N	117	18	22	122,778	17,768	23,369
		%	12.4	3.6	12.4	12.7	3.4	13.0
	Single, Never Married	N	124	29	61	117,826	30,938	62,046
		%	13.1	5.7	34.3	12.2	5.9	34.6
	Not Applicable	N	4	6	13	5,231	5,530	12,260
		%	0.4	1.2	7.3	0.5	1.1	6.8
	Prefer not to answer / Do not know	N	2	2	0	2,245	1,888	0
		%	0.2	0.4	0.0	0.2	0.4	0.0

Source: Primary data collected through the MS Impact Survey.

**Exhibit E-2. Total individual earnings in 2019**

		Unweighted				Weighted			
		MS	PC	SC	Household	MS	PC	SC	Household
<b>Total</b>		<b>918</b>	<b>491</b>	<b>160</b>	<b>916</b>	<b>937,609</b>	<b>506,767</b>	<b>162,151</b>	<b>932,802</b>
<b>&lt;\$1,000</b>	N	183	52	30	61	194,524	63,913	29,282	72,068
	%	19.9	10.6	18.8	6.7	20.7	12.6	18.1	7.7
<b>\$1,000- \$25,000</b>	N	197	95	40	98	204,360	103,049	39,628	103,405
	%	21.5	19.3	25.0	10.7	21.8	20.3	24.4	11.1
<b>\$25,000- \$50,000</b>	N	179	111	30	147	179,123	109,661	31,278	149,003
	%	19.5	22.6	18.8	16.0	19.1	21.6	19.3	16.0
<b>\$50,000- \$75,000</b>	N	135	82	17	165	130,507	80,957	17,726	166,733
	%	14.7	16.7	10.6	18.0	13.9	16.0	10.9	17.9
<b>\$75,000- \$100,000</b>	N	74	45	13	101	73,561	45,179	14,326	98,933
	%	8.1	9.2	8.1	11.0	7.8	8.9	8.8	10.6
<b>\$100,000- \$125,000</b>	N	29	23	6	89	30,536	22,598	5,556	89,534
	%	3.2	4.7	3.8	9.7	3.3	4.5	3.4	9.6
<b>\$125,000- \$150,000</b>	N	26	16	2	57	25,908	15,886	2,245	55,479
	%	2.8	3.3	1.3	6.2	2.8	3.1	1.4	5.9
<b>\$150,000- \$175,000</b>	N	8	17	2	47	8,442	16,825	2,084	47,095
	%	0.9	3.5	1.3	5.1	0.9	3.3	1.3	5.1
<b>\$175,000- \$200,000</b>	N	10	3	1	20	9,869	2,697	809	19,323
	%	1.1	0.6	0.6	2.2	1.1	0.5	0.5	2.1
<b>&gt;\$200,000</b>	N	19	11	1	63	19,735	10,838	944	62,414
	%	2.1	2.2	0.6	6.9	2.1	2.1	0.6	6.7
<b>Prefer not to answer</b>	N	58	36	18	68	61,045	35,164	18,274	68,815
	%	6.3	7.3	11.3	7.4	6.5	6.9	11.3	7.4

Note: The total earnings includes the amount received through wages, salary, commissions, overtime pay, or tips from all jobs before taxes or other deductions, and exclude any social security income, Supplemental Security Income (SSI), or Social Security Disability Insurance (SSDI). The household includes all family members living with the Person with MS, and excludes co-residents who are financially independent and all paid care partners who are not family members.

**Exhibit E-3. Symptom severity for persons with MS**

	Unweighted		Weighted	
	Frequency	Percent	Frequency	Percent
<b>Total</b>	<b>946</b>	<b>100.0</b>	<b>965,184</b>	<b>100.0</b>
Has mild MS symptoms that do not limit activities of daily living	147	15.5	142,745	14.8
Has mild MS symptoms such as sensory problems, mild bladder problems, mild incoordination or weakness, and fatigue, but there is no significant problem with walking.	346	36.6	331,857	34.4
Has significant problems walking, but does not use any type of walking aid.	65	6.9	62,813	6.5
Can walk 25 feet without a cane or some other form of support, such as a splint, brace, or crutch but uses them occasionally or for walking longer distances.	98	10.4	99,558	10.3
To be able to walk 25 feet, must use a cane or some other form of support on one side such as holding on to furniture or touching the wall.	113	11.9	120,940	12.5
To be able to walk 25 feet, must use two canes, a walker, or two crutches.	93	9.8	107,426	11.1
The only form of mobility is a wheelchair or a scooter.	79	8.4	93,338	9.7
Completely bedridden (unable to sit in a wheelchair for more than an hour).	3	0.3	4,618	0.5
Do not know	2	0.2	1,888	0.2

Source: Primary data collected through the MS Impact Survey.

### Exhibit E-4. Health conditions among persons with MS

Condition	Unweighted		Weighted	
	Frequency	Percent	Frequency	Percent
<b>Total</b>	<b>946</b>	<b>100.0</b>	<b>965,184</b>	<b>100.0</b>
Depression	449	47.5	445,571	46.2
Anxiety	379	40.1	366,240	37.9
Hypertension (high blood pressure)	250	26.4	270,909	28.1
Hyperlipidemia (high cholesterol)	153	16.2	164,317	17.0
Fibromyalgia	52	5.5	50,695	5.3
Chronic lung disease	30	3.2	33,070	3.4
Epilepsy	19	2.0	18,604	1.9
Bipolar Disorder	24	2.5	22,127	2.3
Irritable bowel syndrome (IBS)	117	12.4	117,884	12.2
Inflammatory bowel disease	28	3.0	30,653	3.2
Psoriasis	63	6.7	63,332	6.6
Ischemic heart disease	10	1.1	15,531	1.6
Diabetes	59	6.2	63,101	6.5
Gastrointestinal diseases	87	9.2	89,168	9.2
Thyroid diseases	170	18.0	172,539	17.9
Arthritis	186	19.7	200,702	20.8
Other	175	18.5	176,354	18.3
None of the above	0	0.0	0	0.0

Source: Primary data collected through the MS Impact Survey.

- <sup>1</sup> Wallin MT, Culpepper WJ, Campbell JD, Nelson LM, Langer-Gould A, Marrie RA, Cutter GR, Kaye WE, Wagner L, Tremlett H, Buka SL, Dilokthornsakul P, Topol B, Chen LH, and LaRocca NG. The prevalence of MS in the United States. A population-based estimate using health claims data. *Neurology*. 2019;92:e1029-e1040. doi:10.1212/WNL.0000000000007035
- <sup>2</sup> Mayo Clinic. Multiple Sclerosis. Last accessed on 3/2/2021. <https://www.mayoclinic.org/diseases-conditions/multiple-sclerosis/symptoms-causes/syc-20350269>
- <sup>3</sup> National MS Society, The health impact of multiple sclerosis, 2019.
- <sup>4</sup> O’Gorman C, Lucas R, Taylor B. Environmental risk factors for multiple sclerosis: a review with a focus on molecular mechanisms, *Int J Mol Sci*. 2012;13(9): 11718-11752.
- <sup>5</sup> Dehghani A, Khoramkish M, Shahsavari Isfahani S. Challenges in the Daily Living Activities of Patients with Multiple Sclerosis: A Qualitative Content Analysis. *Int J Community Based Nurs Midwifery*. 2019;Jul;7(3):201-210. doi: 10.30476/IJCBNM.2019.44995.

- 
- <sup>6</sup> Kobelt G, Langdon D, Jönsson L. The effect of self-assessed fatigue and subjective cognitive impairment on work capacity: The case of multiple sclerosis. *Mult Scler J*. 2019;Apr;25(5):740-9.
- <sup>7</sup> Centers for Medicare and Medicaid. <https://www.cms.gov/Research-Statistics-Data-and-Systems/Files-for-Order/LimitedDataSets/StandardAnalyticalFiles>
- <sup>8</sup> <https://www.medicare.gov/medicaid/data-systems/macbis/medicaid-chip-research-files/transformed-medicare-statistical-information-system-t-msis-analytic-files-taf/index.html>
- <sup>9</sup> <https://www.optum.com/business/solutions/data-analytics/data/real-world-data-analytics-a-cpl/claims-data.html>
- <sup>10</sup> Centers for Disease Control and Prevention. <https://www.cdc.gov/policy/polaris/economics/cost-illness/index.html>
- <sup>11</sup> Whetten-Goldstein K, Sloan FA, Goldstein LB, Kulas ED. A comprehensive assessment of the cost of multiple sclerosis in the United States. *Mult Scler*. 1998 Oct;4(5):419-25. doi: 10.1177/135245859800400504. PMID: 9839302.
- <sup>12</sup> Kobelt G, Berg J, Atherly D, Hadjimichael O. Costs and quality of life in multiple sclerosis: a cross-sectional study in the United States. *Neurology*. 2006;66(11):1696-702.
- <sup>13</sup> Finkelsztejn A. Multiple sclerosis: overview of disease-modifying agents. *Perspect Medicin Chem*. 2014;6:65-72. doi:10.4137/PMC.S13213
- <sup>14</sup> Iezzoni LI, Ngo L. Health, disability, and life insurance experiences of working-age persons with multiple sclerosis. *Mult Scler*. 2007;13:534-546.
- <sup>15</sup> Owens GM. Economic burden of multiple sclerosis and the role of managed care organizations in multiple sclerosis management. *Am J Manag Care*. 2016;22:S151-S158.
- <sup>16</sup> Wide-ranging Online Data for Epidemiologic Research (WONDER): <https://wonder.cdc.gov/>
- <sup>17</sup> Bureau of Labor Statistics Reports. Highlights of women's earnings in 2018. Report 1083. November 2019. <https://www.bls.gov/opub/reports/womens-earnings/2018/home.htm>
- <sup>18</sup> Marrie RA. Comorbidity in multiple sclerosis: past, present and future. *Clin Invest Med*. 2019;23;42(1):E5-E12. doi: 10.25011/cim.v42i1.32383.
- <sup>19</sup> Max W, Rice DP, Sung HY, Michel M: Valuing Human Life: Estimating the Present Value of Lifetime Earnings, 2000. San Francisco, CA, Institute for Health & Aging, 2002.
- <sup>20</sup> Morrow RH, Bryant JH. Health policy approaches to measuring and valuing human life: conceptual and ethical issues. *Am J Public Health*. 1995;85(10):1356-1360.
- <sup>21</sup> West RR, McNabb R, Thompson AGH, Sheldon TA, Grimley Evans J. Estimating implied rates of discount in healthcare decision-making. *Health Technol Assess Winch Engl*. 2003;7(38):1-60.
- <sup>22</sup> See <https://www.bls.gov/opub/reports/womens-earnings/2018/home.htm> Table 1 and Table 4 for more information.
- <sup>23</sup> CDC: National Vital Statistics Reports, Vol 68, No 7, June 24th, 2019. Available here: [https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68\\_07-508.pdf](https://www.cdc.gov/nchs/data/nvsr/nvsr68/nvsr68_07-508.pdf)
- <sup>24</sup> Heinonen T, Castrén E, Luukkaala T, Mäkinen K, Ruutiainen J, Kuusisto H. The retirement rate due to multiple sclerosis has decreased since 1995 - A retrospective study in a Finnish central hospital. *Mult Scler Relat Dis*. 2020;45:102360.
- <sup>25</sup> Independent Sector “The Current Estimated National Value of Each Volunteer Hour Is \$27.20”, July 20, 2019. Last accessed on 1/21/2021. <https://independentsector.org/value-of-volunteer-time-2020/>
- <sup>26</sup> Dieleman JL, Cao J, Chapin A, et al. US Health Care Spending by Payer and Health Condition, 1996-2016. *JAMA*. 2020;323(9):863–884. doi:10.1001/jama.2020.0734
- <sup>27</sup> Larkindale J, Yang W, Hogan PF, Simon CJ, Zhang Y, Jain A, Habeeb-Louks EM, Kennedy A, Cwik VA. Cost of illness for neuromuscular diseases in the United States. *Muscle Nerve*. 2014;49(3):431-8.



- 
- <sup>28</sup> Yang, W., Hamilton, J.L., Kopil, C. et al. Current and projected future economic burden of Parkinson's disease in the U.S.. *npj Parkinsons Dis.* 2020;6, 15. <https://doi.org/10.1038/s41531-020-0117-1>.
- <sup>29</sup> Hall, Michael H. "Measurement issues in surveys of giving and volunteering and strategies applied in the design of Canada's National Survey of Giving, Volunteering and Participating." *Nonprofit and Voluntary Sector Quarterly* 30.3 (2001): 515-526.