

Supplemental Materials

Supplementary Tables A1 – A5 show the breakdown of survey respondents, based on how they describe themselves, and based on their demographic characteristics. Nearly 70% of respondents had relapsing-remitting MS; secondary-progressive MS was the second most common type of MS among the survey respondents (16.9%). The average duration of MS since the first symptoms was 19.8 years, ranging from 0 to 61 years. More than 50% of PwMS reported that they had received care from a primary caregiver (PC) in 2019, and nearly 19% of PwMS additionally received unpaid care from a secondary caregiver (SC). About 50% of PwMS were between age 45 and 64, 74% were females, and 87% were White or Caucasian.

Table A1. 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
Sub-total	946	
Do not have MS, no one in the family had MS, and do not know anyone with MS	3	0.3
Total number of respondents	949	100

Source: Primary data collected through the MS Impact Survey.

Table A2. Sample breakdown by type of MS

	Unweighted		Weighted	
	Frequency	Percent	Frequency	Percent
Total	946	100.0	965,184	100.0
Relapsing-Remitting MS (RRMS)	676	71.5	667,366	69.1
Primary-Progressive MS (PPMS)	93	9.8	100,806	10.4

	Unweighted		Weighted	
	Frequency	Percent	Frequency	Percent
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.

Table A3. Disease duration since first symptom and since diagnosis for MS patients

	Unweighted		Weighted	
	Frequency	Percent	Frequency	Percent
Duration since the first symptom				
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
Total	946	100	965,184	100
Mean (No. of Years)	18.7		19.8	
Duration since diagnosis				
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
Total	946	100	965,184	100
Mean (No. of Years)	13.6		14.4	

Source: Primary data collected through the Survey.

Table A4. Percentage of MS patients who received unpaid care from a caregiver in 2019

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

Table A5. Demographic characteristics of the MS patients and unpaid caregivers

			Unweighted			Weighted		
			MS	PC	SC	MS	PC	SC
All			946	506	178	965,184	522,371	179,485
Age	<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
Gender	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
Race / Ethnicity	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
		%	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 Survey. MS: MS Patients. PC: Primary caregivers. SC: Secondary caregivers.

Table A6. Percent of MS patients treated with DMT and per capita DMT cost (in 2019)

Gender	Age	% of MS patients 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^{Error! Bookmark not defined.}, 2017-2019 Medicare 5% sample claims^{Error! Bookmark not defined.}, and the 2018 Medicare Current Beneficiary Survey^{Error! Bookmark not defined.}. DMT: disease-modifying therapies.

Supplementary Materials 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**.

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.

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

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’

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_____

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.*

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.*

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

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

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

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).

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"/>

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.

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.

State _____

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

	Person with MS	Primary Caregiver	Secondary Caregiver
Year			

	Male	Female	Prefer not to answer
Person with MS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Primary Caregiver	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Secondary Caregiver	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

[illegible]

	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
Primary Caregiver	<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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Secondary Caregiver	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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.

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

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.

	Person with MS	Primary Caregiver	Secondary Caregiver
Married	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Unmarried but living with partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Widowed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Divorced/ Separated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Single, Never Married	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Prefer not to answer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Person with MS	Primary Caregiver	Secondary Caregiver
Not Applicable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do not know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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.**

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

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.

	Total Amount In 2019 (\$ Before Tax) (If the Person with MS was not eligible or did not receive any of the following, enter 0.)
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Financial assistance received from charitable organizations or other assistance programs (does not include goods or services, monetary contributions only)	_____
Supplemental Security Income (SSI) 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.	_____
Social Security Disability Insurance (SSDI) 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	_____

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.

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"/>

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.

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

	Individual Coverage	Family Coverage	No Coverage
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"/>

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.

	Amount (\$) Spent by Household in 2019 (not spent by insurance or charitable organization)

		(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	_____

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.

	Amount (\$) Spent by Household in 2019 (not spent by insurance or charitable organization) (enter 0 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	_____

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.

		Amount (\$) Spent by Household in 2019 (not spent by insurance or charitable organization) (enter 0 in the text box if no money was spent)
a.	Expenses related to purchasing/installing/modifying special equipment at home or on a personal family vehicle (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.	Expenses on home modifications (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 hiring someone , 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 transportation costs 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)	_____

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.

	Year first began to provide care and assistance to the Person with MS
Primary Caregiver	_____
Secondary Caregiver	_____

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

	Person with MS	Primary Caregiver	Secondary Caregiver
Employed full-time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Employed part-time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not employed, but seeking work (unemployed)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not employed, but in school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not employed, not seeking work and not in school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Retired	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not applicable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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?

	Yes, MS played a role	No, MS did not play a role
Person with MS	<input type="checkbox"/>	<input type="checkbox"/>
Primary Caregiver	<input type="checkbox"/>	<input type="checkbox"/>
Secondary Caregiver	<input type="checkbox"/>	<input type="checkbox"/>

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.

	Year moved to part-time work	Year became unemployed	Year retired or stopped working
Person with MS	_____	_____	_____

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.

	Year moved to part-time work	Year became unemployed	Year retired or stopped working
Primary Caregiver	_____	_____	_____

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.

	Year moved to part-time work	Year became unemployed	Year retired or stopped working
Secondary Caregiver	_____	_____	_____

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?

	Person with MS	Primary Caregiver	Secondary Caregiver
Hours worked in a typical week in 2019	_____	_____	_____

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.

	Person with MS	Primary Caregiver	Secondary Caregiver
Months employed in 2019	_____	_____	_____

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	_____
Primary Caregiver	_____
Secondary Caregiver	_____

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	_____
Primary Caregiver	_____
Secondary Caregiver	_____

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	0	1	2	3	4	5	6	7	8	9	10
Primary Caregiver	0	1	2	3	4	5	6	7	8	9	10
Secondary Caregiver	0	1	2	3	4	5	6	7	8	9	10

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	Secondary Caregiver
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"/>

	Person with MS	Primary Caregiver	Secondary Caregiver
Chose not to take a job because the current job has better benefits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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"/>

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). Enter '0' for activities that the person does not engage in.*

		Hours spent by the Person with MS on volunteering BEFORE MS started having a significant impact	Hours spent by the Person with MS on volunteering AFTER 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	_____	_____

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?

		Hours spent by the Primary Caregiver on volunteering BEFORE MS started having a significant impact	Hours spent by the Primary Caregiver on volunteering AFTER 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	_____	_____
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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?

		Hours spent by the Secondary Caregiver on volunteering BEFORE MS started having a significant impact	Hours spent by the Secondary Caregiver on volunteering AFTER 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	_____	_____