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Economic Burden and Future Impact of Parkinson's Disease

Final Report

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Acknowledgement

Lewin Group Project Staff

Grace Yang, MPA, MA
Laura Schmiel, BS
Matt Zhou, BS
Inna Cintina, PhD
Donna Spencer, PhD
Paul Hogan, MS

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Executive Summary

Parkinson's disease (PD) is a slowly progressive neurodegenerative disorder that affects approximately one million Americans.[1] In addition to the debilitating symptoms of PD itself, patients also experience a number of comorbidities, such as anxiety, depression, increased rates of infection, cardiac and gastrointestinal diseases, and injuries from falls.[2,3] As a result, individuals with PD have higher medical needs, often miss work, retire early, and require the assistance of a caregiver. As such, the direct and indirect economic burden of PD is likely to be significant.

As part of its initiative to understand the economic burden of PD, the Michael J. Fox Foundation commissioned The Lewin Group to estimate the economic impact of PD in the U.S. in 2017. This study aims to provide the most comprehensive assessment of the total burden of PD 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 as well as in social life, and caregiver burden.

Methods

We took a prevalence-based approach in estimating the burden of PD in 2017 where the prevalence of PD is combined with per-capita cost to derive national economic burden, by population characteristics. Multiple data sources are used to estimate the cost components of PD. We used the Census population projections combined with Medicare Current Beneficiary Survey (MCBS) and the Medical Expenditure Panel Survey (MEPS) data to estimate the prevalence of PD. We used MCBS, claims data from Medicare Standard Analytical File and Optum de-identified Normative Health Information data, a large claims database for the privately insured, to estimate the direct medical cost of PD. Direct costs were calculated as the difference in total annual paid amount between persons with PD and matched controls (based on age, gender, race/ethnicity, and insurance) without PD. Future earnings loss due to premature deaths attributable to PD was estimated using CDC Wonder data and the Medicare analytical files, among others. 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 PD and their unpaid care partners due to reduced employment;

2. Reduced labor market productivity, including absenteeism and presenteeism, for persons with PD and their unpaid care partners;

3. Productivity loss from reduced participation in social activities for persons with PD and their unpaid care partners;

4. Cost for the government to provide supplement disability income such as Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI); and

5. Non-medical cost of PD such as the cost of hiring professional non-medical caregivers to assist with daily living, home modification costs and increased transportation costs.

Study Highlights

This study provides the most comprehensive assessment of the economic burden of PD in the U.S. in 2017. The estimated total economic burden of PD in 2017 was $51.9 billion, including a direct medical cost of $25.4 billion and an additional $26.5 billion in indirect and non-medical cost. These findings show that the true impact of PD has been previously underestimated in the literature (see the Discussion section).

Another highlight of the study is the Social and Financial Impact of Parkinson's Disease Survey (i.e. the PD Impact Survey). This primary survey was specifically designed and administered for this study to deepen the understanding of the full spectrum of PD impact. The survey was able to collect detailed data on a broad set of indirect and non-medical costs of PD that were previously unavailable, especially the impact of PD on unpaid caregivers. This survey was one of the largest surveys conducted so far on relatively rare neurodegenerative diseases and received almost 5,000 responses from the PD community.

Study Findings

PD prevalence estimated using nationally representative surveys for younger and elderly U.S populations revealed a much higher prevalence than previous literature. **Exhibit ES-1** shows the estimated PD prevalence:

- An estimated 1.04 million individuals in the U.S. have PD in 2017.

- PD is much more prevalent in the ≥65 population than in the younger population.

- More males than females have PD.

- PD prevalence rate is more than double among non-Hispanic White compared to other groups, although this result is not risk-adjusted and is subjected to small sample size limitations.

- Vast majority (89%) of the persons with PD are eligible for Medicare. Among the estimated 919,000 individuals eligible for Medicare coverage, 82,000 (9%) are younger than age 65.

Exhibit ES-1. Parkinson's disease prevalence by population characteristics (in 2017)

	No. of Persons Estimated to Have PD	Population	Prevalence
Age			
≤49	17,000	212,270,000	0.01%
50-64	184,000	63,810,000	0.29%
65-74	385,000	28,860,000	1.33%
≥75	452,000	20,779,000	2.18%
Gender			
Male	595,000	160,355,000	0.37%
Female	443,000	165,364,000	0.27%
Race/Ethnicity			

	No. of Persons Estimated to Have PD	Population	Prevalence
Non-Hispanic White	834,000	197,113,000	0.42%
Non-Hispanic Black	77,000	40,034,000	0.19%
Hispanic	107,000	59,519,000	0.18%
Other	19,000	29,053,000	0.07%
Insurance			
Private	77,000	176,965,000	0.04%
Medicare	919,000	56,213,000	1.63%
Other*	42,000	92,541,000	0.05%

Source: Lewin analyses of 2011-2015 Medical Expenditure Panel Survey (MEPS), 2015 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2017. *Other includes Medicaid, other insurance, and uninsured.

PD is associated with significant amount of excess medical cost: $25.4 billion in 2017, higher than the previous U.S. based estimates. **Exhibit ES-2** shows the estimated direct medical cost of PD.

- The vast majority of the medical cost of PD is borne by populations with Medicare coverage (90%), 7% by those with private insurance, and 3% by those with other insurance including Medicaid, other insurance, or no insurance). Note: the five-year combined MEPS data identified a total of 20 PWPs who are in the Other group, the small sample size prevented further breakdown.

- On average, the excess medical cost of PD is $24,439 above not having PD. Average per-person excess cost is $22,671 and $19,489 for the privately insured and Other group of persons with PD who are younger than 65 years of age, respectively; and $24,811 for the Medicare beneficiary population with PD.

- Hospital inpatient care, non-acute institutional care (including SNF, nursing home, hospice, etc.), and outpatient (including ancillary care) are the three largest cost categories.

Exhibit ES-2. Direct medical cost of Parkinson's disease by age, gender, and insurance coverage (in 2017)

	Total Excess Medical Cost due to PD		Per Capita ($)
	(in Million $s)	Percentage of the Total	
Age			
≤49	490	2%	29,346
50-64	4,153	16%	22,598
65-74	8,858	35%	23,011
≥75	11,847	47%	26,222
Gender			
Male	13,580	54%	22,838
Female	11,768	46%	26,589
Race/Ethnicity			
NH White	17,280	68%	20,708

	Total Excess Medical Cost due to PD		Per Capita ($)
	(in Million $s)	Percentage of the Total	
NH Black	2,708	11%	35,277
Hispanic	4,661	18%	43,766
Other	699	3%	35,876
Insurance			
Private	1,742	7%	22,671
Medicare	22,793	90%	24,811
Other*	812	3%	19,489
Type of service			
Non-acute Institutional Care	7,144	28.2%	6,888
Hospital Inpatient	7,190	28.4%	6,932
Outpatient	5,506	21.7%	5,308
Physician Office	1,226	4.8%	1,182
Durable Medical Equipment	145	0.6%	140
Prescription Medication	4,137	16.3%	3,988
Overall	**25,348**	**100%**	**24,439**

Source: Lewin analyses of PD prevalence using 2011-2015 Medical Expenditure Panel Survey (MEPS), 2015 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2017; combined with direct medical cost estimates using 2016 Optum claims, 2015 Medicare Standard Analytical File 5% sample claims, and 2015 Medicare Current Beneficiary Survey (MCBS). *Other includes Medicaid, other insurance, and uninsured.

The estimated total indirect and non-medical cost of PD is $26.5 billion in 2017, with near $20 billion to persons with PD and another $6.6 billion to unpaid care partners. **Exhibit ES-3** shows the estimated indirect and non-medical cost of PD:

- Average indirect and non-medical cost per PWP is $19,242 for PWP only and $25,558 for PWP combined with caregiver burden.

- Total indirect cost is $14.2 billion with the combined PWP and caregiver absenteeism cost being the largest share, followed by presenteeism cost and premature death related earnings loss. The cost of absenteeism and presenteeism for the care partners even surpass those for the PWPs.

- Total non-medical cost is $7.5 billion with the paid non-medical daily care being the largest share, followed by home modification cost.

- Disability income, although considered transfer cost, is approximately $4.8 billion.

Exhibit ES-3. The indirect and non-medical cost of PD by cost component (in 2017)

	Total Indirect and Medical Costs (in Million $s)			Per Capita ($)		
	PWP Loss	Care Partner Loss	PWP & Care Partner	PWP Loss	Care Partner Loss	PWP & Care Partner
Premature Death	2,508	NA	2,508	2,418	NA	2,418
Reduced Employment	1,873	802	2,675	1,806	773	2,579

	Total Indirect and Medical Costs (in Million $s)			Per Capita ($)		
	PWP Loss	Care Partner Loss	PWP & Care Partner	PWP Loss	Care Partner Loss	PWP & Care Partner
Absenteeism	1,395	3,655	5,050	1,345	3,524	4,869
Presenteeism	1,263	1,684	2,946	1,217	1,623	2,841
Social Productivity Loss in Volunteer Work	623	410	1,034	601	396	997
Disability Income						
Supplemental security income (SSI)	561	NA	561	541	NA	541
Social security disability insurance (SSDI)	1,677	NA	1,677	1,617	NA	1,617
Other disability income	2,521	NA	2,521	2,431	NA	2,431
Non-Medical Costs						
Paid daily non-medical care	3,847	NA	3,847	3,709	NA	3,709
Home modification	2,232	NA	2,232	2,151	NA	2,151
Motor vehicle modification	931	NA	931	897	NA	897
Other expenses	527	NA	527	508	NA	508
Overall	**19,958**	**6,551**	**26,509**	**19,242**	**6,316**	**25,558**

Source: Lewin analyses of PD Impact Survey data, supplemented with other data sources such as CDC Wonder death records, Bureau of Labor Statistics earnings data; combined with prevalence estimated using 2011-2015 Medical Expenditure Panel Survey (MEPS), 2015 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2017.

Discussion

As shown in **Exhibit ES-4**, PD prevalence, direct medical cost, and indirect & non-medical costs estimated in this study are higher than the previous U.S. based PD burden studies,[4,5,6] although the prevalence estimate is similar to a more recent study conducted by the Parkinson's Foundation.[7] While our burden estimates may represent the real growth in PD prevalence and in the increase in the use of health services, most of the difference between our findings and the earlier studies identified are driven by methodological differences. 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. A more detailed comparison is presented in the Discussion section.

Exhibit ES-4: Comparison of the current study with PD burden estimates in the literature

U.S. PD Burden Study	Prevalence	Direct Cost	Indirect & Non-Medical Costs
Current study (2017 cost)	1,040,000	Total: $25,348 M Per capita: $24,439 (in 2017 $s)	Total: $26,509 M Per capita: $25,558 (in 2017 $s)
Kowal 2013 (2010 cost)	630,000	Total: $8,064 M Per capita: $12,805 ($15,749 in 2017 $s)	Total: $6,327 M Per capita: $10,046 ($12,355 in 2017 $s)

U.S. PD Burden Study	Prevalence	Direct Cost	Indirect & Non-Medical Costs
O'Brien 2009 (2007 cost)	500,000	Total: $6,246 M Per capita: $12,491 ($15,823 in 2017 $s)	Total: $4,568 M Per capita:$9,135 ($11,572 in 2017 $s)
Huse 2006 (2003 cost)	645,000	Total: $6,675 M Per capita: $10,349 ($15,654 in 2017$s)	Total: $16,335 M Per capita: $25,326 ($38,308 in 2017 $s)

Source: Lewin estimates of PD burden in comparison with previous studies identified in literature.

A key limitation of the study is the omission of undiagnosed PD. In this study, we focus on the diagnosed PD, due to its significantly higher economic burden and less controversial approach in case identification. A second limitation of the study is the use of private insurance claims to impute cost for the non-private, non-Medicare covered PD population. However, to ensure any intrinsic cost difference between the privately insured and the non-private, non-Medicare population are accounted for, we used the MEPS data and a regression analysis to estimate the cost ratio between the two groups (regardless of their PD status). We then used the cost ratio to adjust the imputed costs. Other limitations are described in the Discussion section of the main body of the report.

Conclusion

This new study provides a comprehensive evaluation of the current and future impact of PD 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 PD of more than $51.9 billion in 2017, including $25.4 in direct medical cost and $26.5 billion in indirect and non-medical costs. This estimate is much higher than previously understood due to both a higher prevalence estimate and a higher per-capita cost (per-capita direct medical cost is $24,439 and indirect and non-medical cost is $25,558 when PWP and care partner losses are combined). PD prevalence estimated using nationally representative surveys for younger and elderly U.S populations revealed a much higher prevalence than previous literature. However, these estimates are in-line with the most recent estimates by the Parkinson's Foundation. Our findings show that PD significantly affects payers, employers, PWPs, and unpaid care partners. The Medicare program bears the largest share of excess medical cost, as most persons with PD are over age 65, while employers experience significant productivity loss from those individuals with PD who are in the labor force, the government spends more on providing disability income, and PWPs and their care partners significantly lose the ability to participate in labor market or volunteer activities.

The findings of this study help underscore the burden of PD 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, disease management by specialists, work-site support, employment and occupational training, and preventive or treatment measures to reduce PD onset and delay PD progression. The findings will inform the decision making in PD related health resource investment and prioritization.

I. Background

Parkinson's disease (PD) is a slowly progressive neurodegenerative disorder that affects approximately one million Americans.[1] In addition to the debilitating symptoms of PD itself, individuals with PD also experience a number of comorbidities, such as anxiety, depression, increased rates of infection, cardiac and gastrointestinal diseases, as well as injuries from falls.[2,3] As a result, individuals with PD have higher medical needs, and incur higher medical costs than they would have should they not have PD.

In addition to increased morbidity, PD may be associated with other excess costs such as the earnings loss due to premature death; indirect productivity loss from early retirement, missed work days, reduced job performance; and increased cost for acquiring the assistance of a caregiver. Persons with PD (PWP) were found to have a higher death rate, especially during the pre-levodopa era. Even after the wide use of levodopa, several studies found that significantly higher death rates were still associated with PD.[8] Although PD onset usually does not happen until later in life, PD can have a severe impact on subsequent labor market attachment among those individuals employed when experiencing symptoms or after receiving a diagnosis. [9,10] Family caregiver burden may represent another critical component of indirect cost burden from PD. For instance, Whetten-Goldstein (1997) reported that family caregivers, particularly spouses, spend an average of 22 hours each week providing care to the PWPs.[11] Despite such evidence, very few recent studies have attempted to quantify the economic burden of PD on unpaid caregivers.

Existing evidence in the literature suggest that the direct and indirect economic burden of PD may be significant. According to several U.S. based studies that examined both the direct medical cost and indirect productivity loss of PD, the total estimated economic burden of PD ranged between $10.8 billion (2007 $s) and $23 billion (2003 $s).[4,5,6] When these numbers are inflated using a 3% general inflation rate, the total burden of PD is approximately $14.5 billion to $34.8 billion in 2017 dollars. A more recent study in 2013 estimated the total burden of PD in 2010 to be $14.4 billion ($17.7 billion in 2017 $s).[4] Among this wide range of total burden estimates of $10.8 billion, $14.4 billion, and $23 billion, the direct medical cost of PD represent approximately 58%, 56%, and 29%.

While these previous studies provide insight into the economic burden of PD, these studies usually include a limited number of cost components due to data limitations, for instance, the omission of Medicare specific data that would be a more accurate source to estimate the PD burden among Medicare beneficiaries that may be particularly affected by PD due to the older age of onset. Other limitations include small sample sizes due to the use of national surveys for healthcare utilization and cost, an inability to account for the severity of the disease, as well as an inability to capture the indirect productivity loss specific to PD (e.g. neurodegenerative disorder is used as a proxy for PD).

This new study aims to provide a more comprehensive assessment of the economic burden of PD 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 PD for the calendar year 2017. We also described a primary survey study, 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 PD community. This survey enables us to estimate the caregiver

burden and more comprehensive measures of labor market consequences for PWPs and their care partners than what is available from secondary data sources; as well as costs associated with adjustments to the disease, such as renovations to homes and motor vehicle modifications, and spending on acquiring professional caregivers.

II. Methods

Due to a lack of a uniform data source and approach to estimate the total burden of PD, we relied on a variety of primary and secondary data sources to estimate different components of the cost of PD, 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 PD, and a human capital approach was used to calculate the indirect cost of PD. 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 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 Parkinson's Disease Prevalence

The prevalence of PD was needed to estimate the total national burden of PD. We estimated the PD prevalence based on two primary data sources to capture PWPs covered by different types of insurance. These two data sources include:

- For Medicare beneficiaries, we used data from the Medicare Current Beneficiary Survey (MCBS). The MCBS is a continuous survey of a representative national sample of 16,000 Medicare beneficiaries, including those who enrolled in Medicare due to their age eligibility as well as those younger than age 65 due to disability eligibility.[12] Ideally we would have liked to combine several years of MCBS to increase the sample size, however, the Centers for Medicare and Medicaid did not publish the MCBS 2014 survey data. Therefore, the 2015 MCBS was used for the PD prevalence estimate. We used three different datasets to identify PWPs. The first was the chronic conditions dataset, which contains survey responses related to chronic and other diagnosed medical conditions. We relied on responses to the questions "Since (month/year) has a doctor ever told you that you had Parkinson's disease" and "Which of these conditions was the cause of your becoming eligible for Medicare" with PD being one of the answers. The second dataset was the facility assessment, which contains assessment information conducted while the beneficiary was a resident in a Medicare approved facility or non-Medicare approved facility. We identified PWPs using a variable indicating that the individual "has Parkinson's Disease". The final dataset was the Minimum Dataset (MDS) dataset, which contains assessment information conducted while the beneficiary was in Medicare certified nursing homes. The PWPs were identified based on variable I5300 indicating "Active diagnosis – Parkinsons". The PWPs identified were then de-duplicated to obtain the unique number of individuals.

- For populations with other types of coverage, including the privately insured and Other (i.e. anyone covered by all other health plans such as Medicaid and VA, as well as those uninsured), we combined the 2011-2015 Medical Expenditure Panel Survey (MEPS) to increase the sample size. Although in the MEPS annual consolidated household survey there are a number of questions asking about the survey respondents' core chronic conditions, PD was not one of them. Therefore we relied on the presence of any PD diagnosis in any of the MEPS chronic condition files to identify PWPs. The ICD-9

diagnosis code included in the publicly available MEPS only contain 3-digits therefore the ICD-9 code 332 was used to identify PD. This means that we have included, in our prevalence estimate, not only individuals with Parkinson's disease (332.0: paralysis agitans), but also some potential cases of 332.1: secondary parkinsonism.[13]

For both data sources, we calculated the annual (or average annual rate in the case of MEPS) prevalence rate of PD by dividing the weighted number of PWPs identified in each age group (≤49, 50-64, 65-74, ≥75), gender, and insurance type (Private, Medicare, Other) by the size of the weighted total population in the age-gender-insurance strata. Due to the very small sample size of the over age 65 population who are covered by non-Medicare insurance, these individuals were assigned to the Medicare group. Population strata-specific prevalence rates were then applied to the 2017 U.S. population obtained from the U.S. Census data to estimate the overall number of PWPs in the U.S. in 2017. The total PD prevalence was combined with the per-capita direct and indirect cost estimates of PD to derive the total national economic burden of PD in 2017, as described in more details below.

Due to the small number of unweighted PWPs identified for insurance types other than private insurance and Medicare, we were unable to breakdown specific insurance types beyond the three groups presented above. Additionally, although racial and ethnic difference in PD prevalence and economic burden is important in understanding the disparity of PD burden, the small sample size for racial groups other than the Non-Hispanic White group prevented the race/ethnicity variable from being included in the age-gender-insurance stratification. Therefore, we only estimated the prevalence of PD by race/ethnicity at the aggregated national level.

We also estimated the prevalence of PD in each U.S. state by extrapolating the national PD prevalence rates to each state's population by age, gender, and race/ethnicity. See results of this secondary analysis in Appendix D.

B. Estimating the Direct Medical Cost

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

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 system, a longitudinally-linked and statistically de-identified database. This research database contains a comprehensive set of medical, prescription drug, and lab claims, membership (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. Although 2017 data

was available, to ensure the completion of the final claims, we used the 2016 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 year 2015 (the latest available at the time of this analysis). 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 the Part D prescription drug claims, nor does it include any benefits not covered by Medicare, such as the long-stay skilled nursing facilities (SNF) claims or nursing home care.

- Due to the fact that Medicare 5% does not include prescription drug and long-term care claims, we used the 2015 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 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 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.

In each of these three databases, we first identified the study group – PWPs – using an algorithm created with the input of the TAG and as shown below:

Step 1. Identify beneficiaries who have continuous coverage for both medical and pharmacy benefits among the privately insured, and with both Medicare Part A and Part B benefits among those covered by Medicare, in the study year;

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

- At least one inpatient claim associated with PD diagnosis code (ICD-9/ICD-10): 332.0/G20, 332.1/G21.11/G21.19/G21.8, 331.82/G31.83, 333.0/G90.3, G23.1, G23.2, 331.6/G31.85; or

- At least two separate outpatient claims associated with the same PD diagnosis codes; or

- At least one outpatient claim with the same PD diagnosis codes and at least one prescription of an antiparkinsonian drug such as carbidopa, levodopa or another PD-related medication. This criteria was only applied to the Optum claims data and the MCBS data as the Medicare 5% data does not include prescription drug claims.

Next, for each PWP included in the study group by insurance coverage, a person without any evidence of PD was matched to the PWP based on age, gender, and race/ethnicity. A 10:1 ratio was used to identify the comparison groups. A comparison of the study and comparison group characteristics are shown in **Exhibit A-1** in Appendix A.

Direct medical cost of PD 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. The other payer portion includes any payments made to the provider by a source other than the individual or the primary health plan, such as the amount paid by a spouse's insurance.

The direct medical cost of PD was estimated by insurance, age, gender, race/ethnicity, and types of healthcare services, including cost of hospital inpatient stay, physician office visit, prescription medications, 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).

Due to a lack of readily available data for the PD population younger than 65 who were either uninsured or covered by insurance types other than private insurance or Medicare, we imputed the cost of this relatively small population with the cost for the same age and gender strata from the Optum claims data for the privately insured. To account for the potential cost differences between the privately covered and the non-privately covered, we estimated a generalized linear model (GLM) with gamma distribution and log link to obtain the cost ratio between the private and the non-private groups. The GLM model included every person under age 65 (regardless if they had PD) and regressed the total annual cost on the insurance indicator of private vs. non-private (excluding Medicare) and covariates age group, gender, and race/ethnicity. The cost ratio estimated was 1.40, indicating that with risk adjustment, the non-privately insured younger population on average costs 28.6% less than the privately insured. We used this ratio to adjust the strata-specific cost from Optum claims data, before using them to impute the cost for the non-private group. The costs imputed included cost of all types of services including long-term care.

C. Estimating the Indirect and Non-Medical Costs

The indirect and non-medical costs of PD is multifaceted and is anticipated to have significant impact on PWPs, their care partners and families. However, information on these cost components is sparse in the literature. This study aims to fill the gap in evidence from the existing literature by addressing six areas of indirect or non-medical cost components of PD, including:

1. Future Earnings Loss due to Premature Death
2. Labor market earnings loss due to reduced employment for PWPs and their unpaid care partners
3. Reduced labor market productivity for PWPs and their unpaid care partners
4. Productivity loss from reduced participation in social activities for PWPs and their unpaid care partners
5. Cost for the government to provide supplement income such as Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI), and
6. Non-medical cost of PD such as the cost of hiring professional non-medical caregivers to assist with daily living, home modification costs and increased transportation costs, etc.

Among these six cost components, item 1 – future earnings loss due to premature death – was estimated using secondary data sources, especially the CDC Wonder data, Medicare 5% sample claims data, and Bureau of Labor Statistics (BLS) earnings data. Items 2-6, were estimated using

data from a primary survey specifically designed for this study – the Social and Financial Impact of Parkinson's Disease.

Below we first describe our methods in estimating the premature death related cost, and then describe the survey development, the survey completion rates, sample characteristics, and how we use the survey questions to conduct the cost estimates for items 2-6 above.

Future Earnings Loss due to Premature Death

In general, PWPs do not die from PD, but rather die with PD. The cause of death of PWPs are often listed as other factors, such as falls leading to serious injuries or fractures, pneumonia or other pulmonary conditions, bronchitis, lung infections, malignant neoplasms, heart diseases, cerebral infarction, septicemia, among others.[14,15,16]

Drawing on data from the CDC Wide-ranging OnLine Data for Epidemiologic Research (WONDER) Detailed Mortality Database, 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 PD.

To calculate loss in earnings, we first estimated the number of premature deaths associated with PD 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 to estimate the national productivity loss of early mortality associated with PD. 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.[17,18,19] 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 PD at age 75 and above).

Calculation of the Number of Premature Deaths Associated with PD

To calculate the number of premature deaths associated with PD in 2017, we first calculated and compared death rates for the PD and non-PD population. We then multiplied the size of the PD population by the difference in death rates to estimate the number of extra (i.e., premature) deaths associated with PD.

Two sources of data were used to calculate the death rates for the PD and non-PD populations: 2016 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 PD were identified based on the presence of at least one diagnosis code for PD as the underlying cause of death or as one of the multiple causes. All other deaths were attributed to the non-PD population. Deaths were estimated for 2017 based on annual trends in the number of deaths between 2014 and 2016.

In the Medicare 5% claims data, we focused our analysis on beneficiaries with at least one month of Part A and B coverage during 2017 and who were identified as having PD 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 PD and non-PD populations because neither data source provided reliable death rates for both the PD and non-PD 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 PD. Death certificates underreport deaths attributed to the disease because PD is often a secondary cause of death and the cause of death of PWPs 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, ESRD).

For these reasons, we used the Medicare 5% data to calculate the death rates for both the elderly PD and non-PD populations and the WONDER data for calculating the death rate for non-elderly population without PD. See **Exhibit B-1** in Appendix B for a comparison of death rates derived from CDC Wonder and Medicare 5% data for the Parkinson's disease and Non-Parkinson's elderly population.

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

- Using the Medicare 5%, we first identified the PD/non-PD 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 (-0.01 for males, -0.19 for females).

- Using the WONDER data, we calculated a death rate for the non-PD population for each age 18-64.

- We calculated the PD/non-PD death ratio for each age 18-64 by applying the average change in the ratio (derived by the regression analysis) to the ratio for each year from 64 to 18.

- We then multiplied the WONDER non-PD death rate for each age 18-64 by the calculated death ratio for the age to derive an estimated PD death rate for each age.

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

Exhibit II-1. Estimated number of premature deaths associated with Parkinson's disease (2017)

	PD Death Rate	Non-PD Death Rate	Difference in Rates (PD - non-PD)	Estimated Number of Premature Deaths for PD
Males				

	PD Death Rate	Non-PD Death Rate	Difference in Rates (PD - non-PD)	Estimated Number of Premature Deaths for PD
≤49 years	0.89%	0.17%	0.71%	18
50-64 years	2.99%	0.95%	2.04%	2,139
65-74 years	7.75%	2.48%	5.27%	13,511
Females				
≤49 years	1.32%	0.12%	1.21%	171
50-64 years	3.39%	0.58%	2.81%	2,219
65-74 years	5.76%	1.61%	4.15%	5,335

Source: Lewin analyses of 2014-2016 CDC Wonder and 2015 Medicare 5% sample claims data. Death rates for ≥65 were derived from Medicare 5% data. Death rates for <65 non-PD population were derived from CDC WONDER data. Death rates for <65 PD population are estimated.

Estimation of the NPV of Productivity Losses

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%). 2016 earnings and employment rates for the U.S. population by gender and age group were obtained from the BLS;[20] survival rates were sourced from the CDC National Vital Statistics Report.[21] 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 PD 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 PD.

The calculation of earnings loss is based on information about annual earnings and adjusts for employment rate and mortality risk by age and gender group. It is important to highlight that all of these inputs were based on publically available statistics for the general U.S. population. We were not able to incorporate PD-specific information on earnings and employment due to a lack of available data. 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 Social and Financial Impact of Parkinson's Disease Survey Study

We designed a primary survey – the Social and Financial Impact of Parkinson's Disease Survey (will hereafter be referred to as the PD Impact Survey), to collect data to estimate the indirect cost

of PD 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 cost of PD, 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 is to help understand the extent of family caregiver burden, which is a critical component of the indirect cost burden of PD.

Survey Design and Sampling

The survey included 40 questions on several key domains, including: 1) health status, disease history and severity of PD; 2) demographic, socio-economic characteristics, and insurance coverage of the PWP; 3) informal caregiver profile and caregiver roles and responsibilities; 4) employment status, productivity, and income of the PWP and caregivers; and 5) non-medical costs. The majority of the questions were close-ended and written at an appropriate literacy level (approximately 8th grade reading level). Given that respondents may be in poor health, we minimized the use of skip patterns, which may be confusing for some respondents. Additionally, we allowed the family member most familiar with the PWP's health to respond to the survey on behalf of the PWP, if the PWP's health prevents 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 PWP and caregiver social wellbeing and financial status. The survey went through several rounds of review and critique by 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 60 MJFF members who have registered in Fox Insight (will hereafter be referred to as the Fox Insight sample), the online longitudinal observational study sponsored by the Foundation aimed at collecting self-reported health data to inform patient-centric therapeutic development research. An additional 40 members volunteered to respond to the test survey. A total of 81 responses were received with 40 of them completing the entire questionnaire and 41 providing incomplete responses. Based on the feedback received from the 40 complete responses and the patterns of attrition from the incomplete responses, we optimized the survey questions, orders and skip logic of questions, and clarified or reduced the difficulty levels of certain questions. The resulting final survey was programmed by MJFF technical support into an online version.

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 an income loss of ±$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 PD.

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. PD population was infeasible. Therefore, we took convenience samples and deployed the survey in two distinct phases, including a 9,421 Fox Insight sample and to additional members of MJFF's UPAC network. The UPAC network consists of 19 partner organizations and 3,000 constituents received the same questionnaire. An examination of the Fox Insight sample characteristics, as compared to that of the PD population identified from the MCBS and MEPS data, showed that the Fox Insight population tend to be younger and have a larger percentage of non-Hispanic White population. Therefore, in reaching out to the additional UPAC members, an emphasis was placed on recruiting the subgroups that are underrepresented in the Fox Insight sample, including seniors, minority groups, and institutionalized PWPs.

Survey Implementation

The survey was administered electronically via two separate modes: one through MJFF's Fox Insight online survey platform, another to a broader audience in the UPAC network through a survey account established in the online survey vendor – Qualtrics. Both the Fox Insight and 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. Links to the online survey were then sent to MJFF and UPAC members via e-mail distribution. Since Qualtrics also manages survey administration on MJFF's Fox Insight platform, the survey formats are compatible between the two platforms and data captured are easily synchronized across the two modes.

Each survey mode was launched among the respective target populations following email introductions of the incoming survey, including its importance to the PD community and logistics of responding to the survey. Each survey mode was open for 3 weeks and up to two rounds of follow-up reminders to non-respondents for completing the survey were sent before the established closing date.

The survey did not include any personally identifiable information. Final datasets were accessible to MJFF and Lewin in a strictly de-identified format to ensure PWP and family confidentiality and privacy.

Survey Completion Rate

Combining the Fox Insight survey sample and the UPAC sample, a total of 6,593 households responded to the survey. Among them, 4,722 (71.6%) completed the survey according to the electronic recording. The additional quality checks revealed that among 4,722 observations that were marked as "completed", there were 105 respondents who did not have answers for a single question. Eliminating them from the dataset reduced the sample size to 4,617 respondents. Additionally, the breakdown of respondents based on how they describe themselves, shows that there were 69 observations that answered that they do not have PD or don't know anyone with PD. Eliminating these 69 responses from the analytic file resulted in the final sample of 4,548 observations. Among the 4,548 respondents included in the final sample, 178 respondents (4%) indicated that the person with Parkinson's (PWP) in their family has passed away. Since they were asked to still fill out the survey based on the PWP's experience within 12 months prior to the death, they were included in the final sample. (**Exhibit II-2**).

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

Which of the following best describes you (the person who is responding to the survey)?	Freq.	Percent
A person with PD	3,098	67.1
A care partner for someone who has PD	1,264	27.4
A family member to someone who has PD, but not a care partner	180	3.9
A close friend of someone who has PD, but not a care partner	6	0.1
Sub-total	4,548	
Do not have PD and do not know anyone with PD	69	1.5
Total number of respondents	4,617	

Source: Primary data collected through the PD Impact Survey

Despite our concerted efforts to recruit a more representative PWP 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 PD population as calculated from the prevalence estimates, and that of the survey respondents found that the survey sample is slightly younger than the prevalent PD population identified using MEPS and MCBS data (see **Exhibit II-6**) and have slightly more males but a similar percentage of the non-Hispanic White subjects. Therefore, we stratified the survey sample and the PD 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-3**, after weighting, about 4% of the survey sample are persons newly diagnosed with PD, another 32% has a disease duration between 1 and 5 years. A little over 56% of the sample has been diagnosed with PD more than 5 years ago. Eight percent of the sample did not answer the question on the year of the diagnosis and therefore has missing disease duration.

Exhibit II-3. Disease duration for persons with Parkinson's

	Unweighted		Weighted	
	Frequency	Percent	Frequency	Percent
N	4,548	100	1,037,211	100
Less than 1 year	206	4.5	40,474	3.9
1-5 years	1,537	33.8	329,114	31.7
5-10 years	1,256	27.6	289,176	27.9
10-15 years	641	14.1	153,504	14.8
15 or more	539	11.9	140,468	13.5
Missing	369	8.1	84,476	8.1

Source: Primary data collected through the PD Impact Survey

A key concern during the survey development phase was the ability of the survey to reach the institutionalized PD population who spent time in the past 12 months in a long-term care facility. As shown in **Exhibit II-4**, more than 6% of our survey sample had spent time at a nursing home during the past 12 months, near 1% at a hospice facility, and another 3.5% in other long-term care facilities. In the claims analysis, we found that about 12% of the PWPs identified in the private claims and more than 18% of PWPs in Medicare (identified from the MCBS) had a claim for nursing home. Although the 6% in the PD Impact Survey sample who stated that they had spent time in a nursing home in the past 12 months is smaller than these claims data based analysis, they do represent a reasonable sample size in capturing the long-term care cost component, which is an important dimension in defining disease severity in the survey, as described in more detail later in the report.

Exhibit II-4. Percentage of persons with Parkinson's who spent time at a long-term care facility in the past 12 months

	Unweighted		Weighted	
	Frequency	Percent	Frequency	Percent
N	4,548	100	1,037,211	100
Private (alone or with someone)	4,284	94.2	955,084	92.1
Nursing home	192	4.2	65,983	6.4
Hospice facility	25	0.55	7,726	0.74
Active adult or senior living community	183	4.0	59,931	5.8
Other "long-term" care facility	115	2.5	35,815	3.5

Source: Primary data collected through the PD Impact Survey

A main purpose of the survey is to estimate the care partner burden, therefore, it is important to understand the extent to which the PWPs are receiving care from an unpaid care partner. As shown in **Exhibit II-5**, after weighting, near 63% of the PWPs reported that they had received care from a primary care partner (PCP) in the past 12 months, and 18.4% of the PWPs received unpaid care from a secondary care partner (SCP).

Exhibit II-5. Percentage of persons with Parkinson's who received unpaid care from a care partner in the past 12 months

		Unweighted		Weighted	
		Frequency	Percent	Frequency	Percent
Received Care from a Primary Care Partner (PCP)	Total	4,548	100	1,037,211	100
	Yes	2,677	58.9	648,185	62.5
	No	1,420	31.2	292,655	28.2
	Not applicable	451	9.9	96,371	9.3
Received Care from a Secondary Care Partner (SCP)	Total	4,548	100	1,037,211	100
	Yes	716	15.7	190,936	18.4
	No	2,748	60.4	594,623	57.3
	Not applicable	1,084	23.8	251,652	24.3

Source: Primary data collected through the PD Impact Survey

Exhibit II-6 shows the demographic and socioeconomic characteristics of the PWPs and the care partners. Without weighting, about 67% of the PWP sample are age 65 and older, 61% are males, and 88% are non-Hispanic White. After weighting, 81% of the PWPs are 65 years or older, more than 57% are males and 89% of the PWPs are non-Hispanic White, matching the distribution of the total PD population characteristics as calculated from MEPS and MCBS. About 69% of the PCPs are seniors and only about 15% of the SCPs are age 65 or older. More than 60% of the PCPs and SCPs are females. Similar to the PWPs, more than 80% of the PCP and SCP samples are non-Hispanic White, and the non-Hispanic Black group is the least represented in the survey.

See Appendix C for additional data on the socio-economic and disease characteristics of the PD Impact Survey sample.

Exhibit II-6. Baseline characteristics of the persons with Parkinson's and unpaid Care partners

			Unweighted			Weighted		
			PWP	PCP	SCP	PWP	PCP	SCP
All			4,548	2,654	683	1,037,211	642,947	182,964
Age	≤49	N	162	204	373	16,695	37,276	84,142
		%	3.6	7.7	54.6	1.6	5.8	46.0
	50-64	N	1,335	811	209	183,767	165,122	72,295
		%	29.4	30.6	30.6	17.7	25.7	38.5
	65-74	N	1,937	1,126	72	384,944	255,939	20,733
		%	42.6	42.4	10.5	37.1	39.8	11.3
	≥75	N	1,101	513	29	451,806	184,609	5,794
		%	24.2	19.3	4.2	43.6	28.7	3.2
	Missing	N	13	.	.	0	.	.
		%	0.3	.	.	0	.	.
Gender	Female	N	1,732	1,882	439	442,580	449,729	119,099
		%	38.1	70.3	61.3	42.7	69.4	62.4
	Male	N	2,764	783	240	594,631	196,100	62,793
		%	60.8	29.3	33.5	57.3	30.2	32.9
	Prefer not to say	N	52	12	37	0	2,357	9,044
		%	1.1	0.4	5.2	.	0.4	4.7
Race/ethnicity	White Non-Hispanic	N	3,989	2,371	585	921,638	574,498	157,285
		%	87.7	88.6	81.7	88.9	88.6	82.4
	Black Non-Hispanic	N	34	29	11	6,295	5,727	2,559
		%	0.7	1.1	1.5	0.6	0.9	1.3
	Other Non-Hispanic	N	138	93	51	30,081	22,670	13,099
		%	3.0	3.5	7.1	2.9	3.5	6.9

			Unweighted			Weighted		
			PWP	PCP	SCP	PWP	PCP	SCP
	Hispanic	N	126	66	20	27,277	17,198	5,855
		%	2.8	2.5	2.8	2.6	2.7	3.1
	Prefer not to say	N	261	118	49	51,920	28, 092	12,138
		%	5.7	4.4	6.8	5.0	4.3	6.4

Source: Primary data collected through the PD Impact Survey

Labor Market Employment related Earnings Loss

PD may increase the likelihood that severe functional impairment or disability prevent PWPs from working, or in some cases limits employment opportunities and reduces earnings. In a Finnish Study, Martikainen et al. (2006) found that PD often led to early retirement. In a sample of 937 PWPs with a median age of 59 years, and a median duration of PD symptoms of 7.3 years, they established that 37% retired exclusively because of PD at a median age of 53.4 years, and that the median employment span was 1.7 years after established diagnosis in this group.[9] Similarly, Schrag & Banks (2006) examined time to loss of employment in two U.K.-based studies of PWPs with onset prior to age 65. They found that the disease led to loss of employment within less than 10 years of disease onset, on average. Furthermore, mean age of retirement among PWPs was 55.8 years compared to an average retirement age of 62 years in the U.K. population. Mean time to loss of employment was 4.9 years, ranging from a mean of 6.7 years in those with onset of PD before age 45 to 1.7 years in those with onset after age 56.[10]

An analysis of our primary survey found that among the working age (18-64) PWPs, 40% are in the labor market, as compared to the national labor force participation rate of 59.7% among the U.S. adult population. To ensure that the early termination of employment was a direct result of PD, we asked survey respondents who have retired or have stopped working if PD had played a major role in their decision to terminate employment. Consequently, the labor market employment related earnings loss due to PD was calculated as the counts of PWPs who retired or stopped working in the past 12 months and indicated that PD played a major role in their early retirement [*Question 32 and Question 33*] multiplied with median annual earnings obtained from American Community Survey (ACS) public use microdata sample (2017). 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 PWPs before retirement was unknown, we used the allocation of full-time to part-time job status among currently working PWPs (for corresponding age and gender stratum) [*Question Q29*]. Then we calculated earnings loss due to early retirement separately for those that retired due to PD and were assumed to be working full-time before retirement and those who were assumed to be working part-time before retirement.

Labor Market Productivity Loss

A chronic disease like PD is likely to result in lower productivity while the PWP and the care partners 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. Two questions in

the PD Impact Survey ask about the number of days in a typical working month during the past 12 months the PWP and the care partners missed work at a job or business or felt less productive while at work, because of PD [*Questions 34 & 35*]. Based on responses to these two questions and the average daily earnings calculated from the self-reported annual earnings [*Question 20*], 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 of 0.31 applied to each day felt unproductive, reflecting that an unproductive day is not equivalent of 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 2017. The adjustment factor of 0.31 was calculated by comparing the annual earnings of PD group vs. non-PD group, controlling for age, gender, race/ethnicity, and education using MEPS data 2011-2015. This number indicates the reduced overall productivity of PD as compared to non-PD.

As Question 20 of the PD survey did not ask about the exact annual earnings but rather asked respondents to indicate which annual income 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 $25,000" were assigned earnings of $12,500; everyone in "$25,000 to less than $50,000" were assigned $37,500; etc.).

Productivity Loss from Forgone Social Activities

In addition to affecting labor market productivity for those who are currently employed, PD may also affect the ability that the PWP and the care partners are able to participate in various social activities using their leisure time. Given that 85% (weighted sample response from the PD survey) of the PD population are older and retired, lower probability of employment and other job-related indicators might not capture the true impact of PD on productivity loss for the older PWPs and care partners who are not working. Even for PWPs and care partners who are still working, the effect of PD may cause them to forgo leisure activities to better cope with the disease. However, the productivity loss due to forgone social activities as a result of PD has been largely neglected in the literature.

To measure time lost from forgone social activities, we asked two questions on the number of hours the PWP and the care partners spent in a typical week before [*Question 38*] and after [*Question 39*] PD 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
3. Participating in a political or community-related organization
4. Visiting with friends or relatives
5. Attending an educational or training course
6. Attending a sporting event or social or other type of club
7. Participating in a religious organization (e.g., church, synagogue, mosque)

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 is our intention to only capture the economic loss due to reduced economic

production of each individual that directly contributes to societal benefits. Therefore, in our social productivity loss related calculations, we focused on activities 1-3 above that are considered directly involving volunteer work and provide a conservative estimate of the social productivity loss.

To evaluate plausibility of reported hours conducting volunteering work, we compared the reported volunteering hours before PD 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 PD Impact Survey (e.g., the average national volunteering hours are 2.5 hours per week [132 hours per-year] and the average hours in the PD survey for PWPs before PD are 14.1 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 with the estimated percentage productivity loss from the PD Impact Survey (calculated as the difference between before and after hours divided by before hours) for the three activities combined.[1]

To place a dollar value on foregone volunteering activities, we used the $24.14 per hour in 2017 dollar value estimated by the Independent Sector.[22] Productivity loss due to forgone volunteering activities was then calculated as: volunteering hours affected per year times $24.14.

D. Estimating the Non-Medical Costs

Disability Income

Naturally, in addition to the economic burden of a disease to the individuals, families, and the 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, the Social Security Disability Insurance (SSDI) and the 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 PD. In the PD survey, we asked a combined question (*Question 23 and 23a*) on whether the PWP had received SSI, SSDI, or other types of disability income (OTDI), in the past 12 months. Based on the proportion of PWPs who answered yes and the average yearly amount received from each source of these disability income, we estimated the average and total disability income due to PD.

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[1]   A small number of survey respondents were shown to have extremely high values on the hours spent on each of the 3 volunteering activities before and after PD started having a significant impact. We therefore, top coded any hours in a week that was more than 56 hours, assuming that no more than 8 hours a day in a 7-day week could be spent on volunteering activities. The estimated reduction in ability to volunteer after the top-coding show similar but smaller reductions.

Other Non-medical Costs

Data from the PD Impact Survey also helps to inform additional personal and family costs associated with PD that are not captured in administrative data or national surveys. These non-medical costs 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. *Question 24* of the PD survey asked about the amount that the PWP or the family had spent in the past 12 months on 4 major non-medical cost categories, as a result of caring for the PWP. 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, visiting PWP who live in nursing home, etc.). 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 average expense per-family per-year, with the total PD population in 2017, by age and gender.

III. Results

A. Parkinson's Disease Prevalence

Exhibit III-1 presents the prevalence of PD by population characteristics. An estimated 1.04 million individuals in the U.S. have PD in 2017. The prevalence of PD increases with age, with the 65 and older persons representing the largest share (81%) of the PD population. Males have a slightly higher prevalence than females, 0.37 percent and 0.27 percent respectfully. The prevalence of PD in non-Hispanic whites is double the prevalence in the non-Hispanic black and Hispanic populations with more than 830,000 in the White subgroup (80% of total PD population). The vast majority (89%) of the PD population are eligible for Medicare coverage.

Exhibit III-1. Parkinson's disease prevalence by population characteristics

	No. of Persons Estimated to Have PD	Population	Prevalence
Age			
≤49	17,000	212,270,000	0.01%
50-64	184,000	63,810,000	0.29%
65-74	385,000	28,860,000	1.33%
≥75	452,000	20,779,000	2.18%
Gender			
Male	595,000	160,355,000	0.37%
Female	443,000	165,364,000	0.27%
Race/Ethnicity			
NH White	834,000	197,113,000	0.42%
NH Black	77,000	40,034,000	0.19%
Hispanic	107,000	59,519,000	0.18%
Other	19,000	29,053,000	0.07%
Insurance			
Private	77,000	176,965,000	0.04%
Medicare	919,000	56,213,000	1.63%
Other	42,000	92,541,000	0.05%

Source: Lewin analyses of 2011-2015 Medical Expenditure Panel Survey (MEPS), 2015 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2017. *Other includes Medicaid, other insurance, and uninsured.

When broken down by age and gender, as in **Exhibit III-2**, males have a higher prevalence of PD than females especially among the older population, with about a one percentage point difference at age 65-74 (1.9% vs. 0.8%) and 75 and older (2.7% vs. 1.8%).

Exhibit III-2. Parkinson's disease prevalence by age and gender
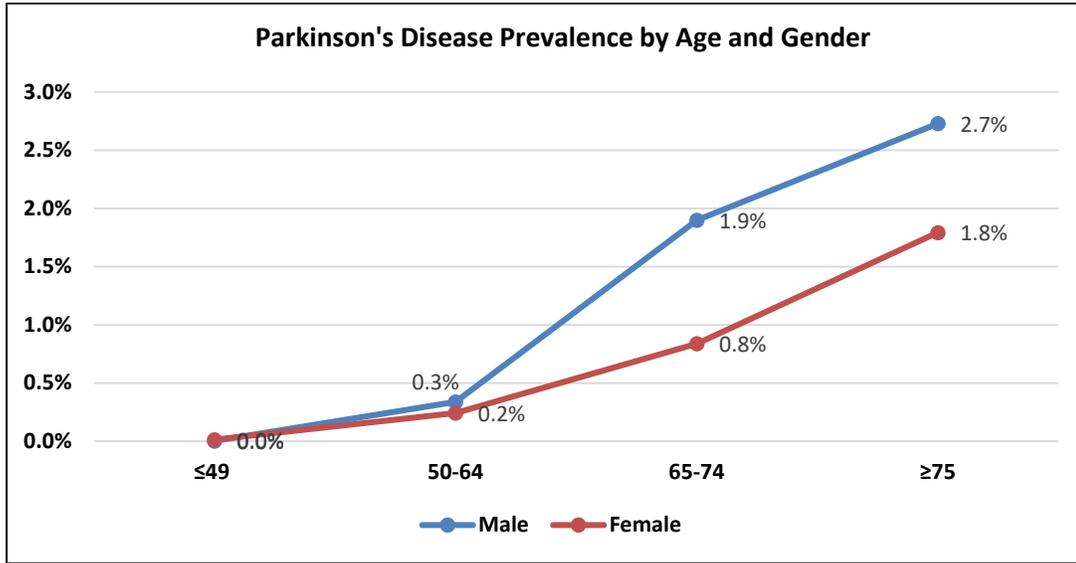
Parkinson's Disease Prevalence by Age and Gender

Source: Lewin analyses of 2011-2015 Medical Expenditure Panel Survey (MEPS), 2015 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2017. *Other includes Medicaid, other insurance, and uninsured.

B. Direct Medical Cost

Exhibit III-3 presents the direct medical cost of PD by population characteristics of age and gender. When compared to a matched comparison group, the direct costs for individuals with PD are substantially higher by age, gender, and insurance coverage (see **Exhibit A-2** in Appendix A). Because of the increased PD prevalence by age, the age groups older than 65 represent more than 80% of total medical cost of PD. Per-person medical cost due to PD increases with age except for the youngest group (≤49), possibly because individuals tend to seek more care when diagnosed at a younger age and the comparison group of these individuals, on the contrary, are the healthiest compared to any PD groups or their comparison groups. Males, although incurring slightly lower per-person cost than female PWPs, have a higher overall direct medical cost burden, due to the higher prevalence of PD among males.

Exhibit III-3. Direct medical cost of Parkinson's disease by age and gender

	Total Excess Medical Cost		Mean Excess Cost due to PD ($)
	Excess Cost (in Million $s)	Percentage of Total	
Males			
≤49 years	76	0.3%	30,506
50-64 years	2,320	9.2%	22,163
65-74 years	5,847	23.1%	22,807
≥75 years	5,337	21.1%	23,096
Females			
≤49 years	414	1.6%	29,144

	Total Excess Medical Cost		Mean Excess Cost due to PD ($)
	Excess Cost (in Million $s)	Percentage of Total	
50-64 years	1,833	7.2%	23,175
65-74 years	3,011	11.9%	23,419
≥75 years	6,510	25.7%	29,495
Overall	25,348	100%	24,439

Source: Lewin analyses of PD prevalence using 2011-2015 Medical Expenditure Panel Survey (MEPS), 2015 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2017; combined with direct medical cost estimates using 2016 Optum claims, 2015 Medicare Standard Analytical File 5% sample claims, and 2015 Medicare Current Beneficiary Survey (MCBS).

Exhibits III-4 through **III-6** break down the total excess medical cost of PD by insurance type and by types of service.

The analysis of direct medical costs by type of service for privately insured PWPs indicates that hospital inpatient and outpatient services are the most costly, when compared to other service types. When compared with their matched comparison group, privately insured PWPs experience a total average excess medical cost of $22,671. (**Exhibit III-4**).

Exhibit III-4. Direct medical cost by types of service (privately insured)
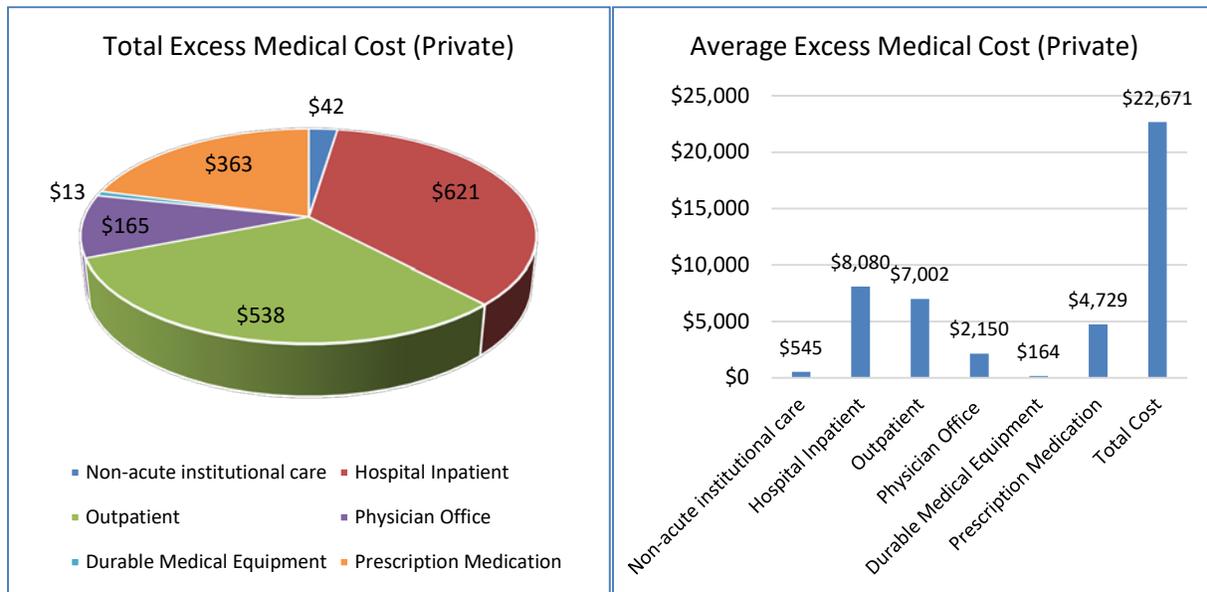
Source: Lewin analyses of PD prevalence using 2011-2015 Medical Expenditure Panel Survey (MEPS), 2015 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2017; combined with direct medical cost estimates using 2016 Optum claims.

Exhibit III-5 shows that, unlike individuals with PD who are privately insured, those who are Medicare eligible experience higher costs in non-acute institutional care ($7,087 million) and hospital inpatient services ($6,293 million), with outpatient services ($4,661 million) a close third. Similar to the group of individuals with private insurance ($22,671), individuals with PD who are

eligible for Medicare, when compared with their matched comparison group, experience a total average excess medical cost of $24,811.

Exhibit III-5. Direct medical cost by types of service (Medicare eligible)
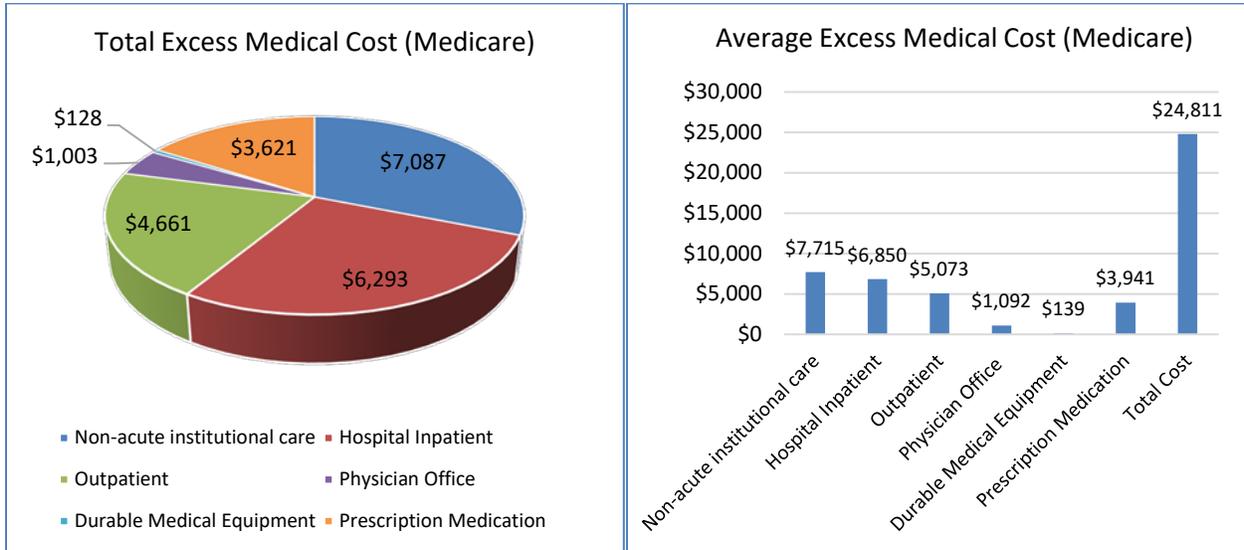
Source: Lewin analyses of PD prevalence using 2011-2015 Medical Expenditure Panel Survey (MEPS), 2015 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2017; combined with direct medical cost estimates using 2015 Medicare Standard Analytical File 5% sample claims and 2015 Medicare Current Beneficiary Survey (MCBS).

Direct medical costs of PD by types of service for those who are either uninsured or covered by other insurances are similar to those who are privately insured. Outpatient services and hospital inpatient care are the most costly, when compared to other service types utilized. For this group, the average annual total average excess medical cost is $19,489, slightly lower than that of the privately insured, as seen in **Exhibit III-6.**

Exhibit III-6. Direct medical cost by types of service (other insurance or uninsured)
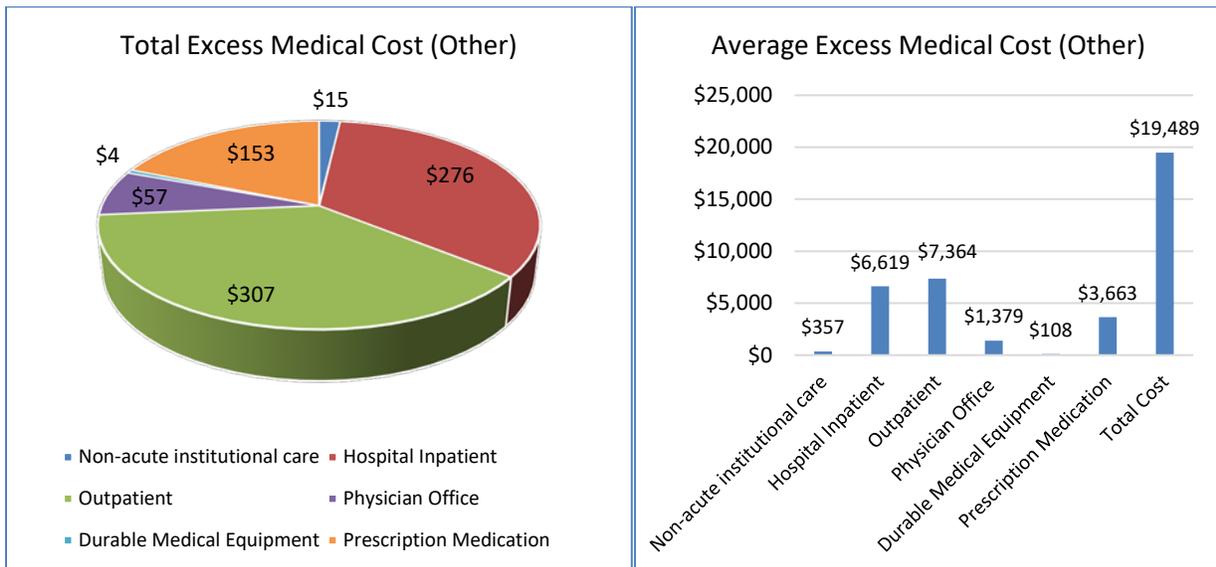
C. Indirect Costs

Premature Death-related Future Earnings Loss

Exhibit III-7 below presents the estimated future earnings loss associated with premature deaths due to PD. As anticipated, the average present value of future earnings per death is lower for each older age group and for women, per the expected remaining years of life and gender differences in labor force participation rates and earnings. In summary, we estimate an average of $107,214 in lost earnings per premature death for a total of $2.5 billion.

Exhibit III-7. Estimated net present value of the future earnings loss for premature deaths associated with Parkinson's disease

	Estimated Number of Premature Deaths	Estimated Present Value of Future Earnings/Death ($)	Estimated NPV (in Million $s)
Males			
≤49 years	18	909,826	16
50-64 years	2,139	345,062	738
65-74 years	13,511	57,337	775
Females			
≤49 years	171	769,680	132
50-64 years	2,219	283,802	630
65-74 years	5,335	40,774	218
Overall	**23,393**	**107,214**	**2,508**

Source: Lewin analyses of 2014-2016 CDC Wonder and 2015 Medicare 5% sample claims data. Death rates for ≥65 were derived from Medicare 5% data. Death rates for <65 non-PD population were derived from CDC WONDER data. Death rates for <65 PD population are estimated. Average earnings by age and gender obtained from Bureau of Labor Statistics.

Labor Market Employment related Earnings Loss

In examining the employment status, about 5% of the persons with PD (PWP), 3% of the primary care partners (PCP), and only 1% of the secondary care partners (SCP) reported that they are no longer working and PD played a major role in their decision to stop working. The total estimated earnings loss due to PD related unemployment is $1.87 billion for PWPs, $716 million for PCPs, and $86 million for the SCPs. Among the PWP group, males age 50-74 incurred the highest earnings loss both because the higher PD prevalence among males and the higher earnings power of this group. Among the PCP group, females age 50-74 incurred the highest earnings loss, due to the fact that females of this age group are most likely to be the primary care partners. (**Exhibit III-8**).

Exhibit III-8. Estimated labor market earnings loss due to Parkinson's disease related unemployment

	PWP		PCP		SCP	
	Percentage Retired and Stopped Working due to PD	Total Earnings Loss (in Million $s)	Percentage Retired and Stopped Working due to PD	Total Earnings Loss (in Million $s)	Percentage Retired and Stopped Working due to PD	Total Earnings Loss (in Million $s)
Males						
≤49 years	4%	5	4%	20	1%	13
50-64 years	13%	719	4%	67	0%	0
65-74 years	6%	543	3%	75	0%	0
≥75 years	1%	58	2%	34	0%	0
Females						
≤49 years	13%	55	3%	25	1%	11
50-64 years	11%	321	7%	337	3%	63
65-74 years	5%	150	3%	146	0%	0
≥75 years	1%	23	1%	11	0%	0
Overall	**5%**	**1,873**	**3%**	**716**	**1%**	**86**

Source: Primary data collected through the PD Impact Survey, combined with average earnings from Bureau of Labor Statistics, and PD prevalence estimated by Lewin.

Labor Market Productivity Loss

Exhibit III-9 displays the percentage of PWPs and their unpaid care partners who were employed in the past 12 months. For PWP, PCP, and SCPs alike, the probability of labor market employment decrease with age and are in general higher among male adults younger than 65 than among females of similar age.

Exhibit III-9. Percentage of persons with Parkinson's and unpaid care partners employed in the past 12 months

	PWP		PCP		SCP	
	Total Population	% Employed	Total Population	% Employed	Total Population	% Employed
Males						
≤49 years	2,481	69%	11,334	80%	32,054	77%
50-64 years	104,677	38%	31,543	68%	23,081	71%
65-74 years	256,381	12%	64,414	16%	7,143	47%
≥75 years	231,092	3%	88,717	8%	1,559	9%
Females						
≤49 years	14,213	51%	27,284	57%	53,098	76%
50-64 years	79,090	39%	133,078	58%	49,556	66%

LEWINGROUP

	PWP		PCP		SCP	
	Total Population	% Employed	Total Population	% Employed	Total Population	% Employed
65-74 years	128,563	8%	195,704	17%	12,722	29%
≥75 years	220,714	3%	96,720	5%	4,799	13%
Overall	**1,037,211**	**13%**	**648,795**	**28%**	**184,011**	**66%**

Source: Primary data collected through the PD Impact Survey, combined with PD prevalence estimated by Lewin.

As shown in **Exhibit III-10**, male PWPs on average lose more work days in a typical working month than female PWPs, except for the youngest age group (≤49 years). While male PCPs in the youngest age group lose more days from work than female PCPs of similar age, the older female PCPs in general lose more work days than their male counterparts. On average, the PCP group lose more work days (6 days) than both the PWP (3.3 days) and the SCP (3.7 days) groups. The total annual absenteeism is the highest for the PCPs ($2.6 billion), followed by PWPs ($1.4 billion), and the SCPs ($1 billion).

Exhibit III-10. Estimated productivity loss due to Parkinson's disease related absenteeism

	PWP		PCP		SCP	
	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)
Males						
≤49 years	3.7	19	6.5	140	2.9	123
50-64 years	3.7	529	6.0	476	3.1	115
65-74 years	2.9	294	3.0	93	4.7	46
≥75 years	4.9	114	4.6	119	0.0	0
Females						
≤49 years	5.0	106	4.7	170	4.1	399
50-64 years	3.2	262	6.4	1,175	4.3	337
65-74 years	2.4	45	6.4	406	1.9	13
≥75 years	1.3	26	9.8	44	0.0	0
Overall	**3.3**	**1,395**	**6.0**	**2,622**	**3.7**	**1,033**

Source: Primary data collected through the PD Impact Survey, combined with PD prevalence estimated by Lewin.

As shown in **Exhibit III-11**, in a typical working month, the PWPs on average have close to 10 days feeling less productive than their norm, because of PD, followed by the PCPs (8.9 days), and the SCPs (5.5 days). To take a conservative approach, we did not count the full number of days felt less productive in the presenteeism calculations, rather we assumed that only a certain portion of the unproductive days was lost due to PD. Therefore, we applied an adjustment factor of 0.31 as 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 $1.3 billion for the PWPs, $1.2 billion for PCPs, and $473 million for the SCPs.

Exhibit III-11. Estimated productivity loss due to Parkinson's disease related presentism (in million $s)

	PWP		PCP		SCP	
	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)
Males						
≤49 years	11.1	17	6.9	46	4.2	56
50-64 years	11.0	491	7.8	191	4.9	56
65-74 years	8.6	268	7.4	71	4.1	12
≥75 years	9.6	69	7.3	58	0.0	0
Females						
≤49 years	12.4	81	7.1	79	5.1	152
50-64 years	10.9	277	10.0	573	7.4	182
65-74 years	8.3	49	9.1	180	6.4	13
≥75 years	1.7	11	9.1	13	0.0	0
Overall	**9.7**	**1,263**	**8.9**	**1,211**	**5.5**	**473**

Source: Primary data collected through the PD Impact Survey, combined with PD prevalence estimated by Lewin.

Productivity Loss from Forgone Social Activities

The impact of PD 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 actual hours reported totaled more than the maximum number of hours in a week (168 hours) for 1-3% of the sample. Because of these outliers and the possible overlap of hours for other survey respondents, the total volunteering hours self-reported were 2-6 times higher than the national numbers, depending on the group (e.g. PWP or care partner) or the time period (BEFORE to AFTER PD 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 the volunteer activities from BEFORE to AFTER PD started to have a major impact, using the responses to the PD Impact Survey. We then applied the social productivity reduction (in percentages) to the average hours each individual is expected to volunteer, based on his or her age and gender, and without the impact of PD, to calculate the hours lost from volunteering activities due to PD. The estimated hours lost due to PD were then multiplied with the

average value of each volunteer hour of $24.24 as estimated by the Independent Sector to quantify the economic value of social productivity loss.[23]

Exhibit III-12 shows that a higher percentage of U.S. female adults perform volunteer work than males however spend fewer hours volunteering than males among those who do volunteer. Regardless of gender, older Americans (≥65 years) tend to spend more hours volunteering.

Exhibit III-12: Percentage of Americans volunteered in the past 12 months and the average number of hours volunteered
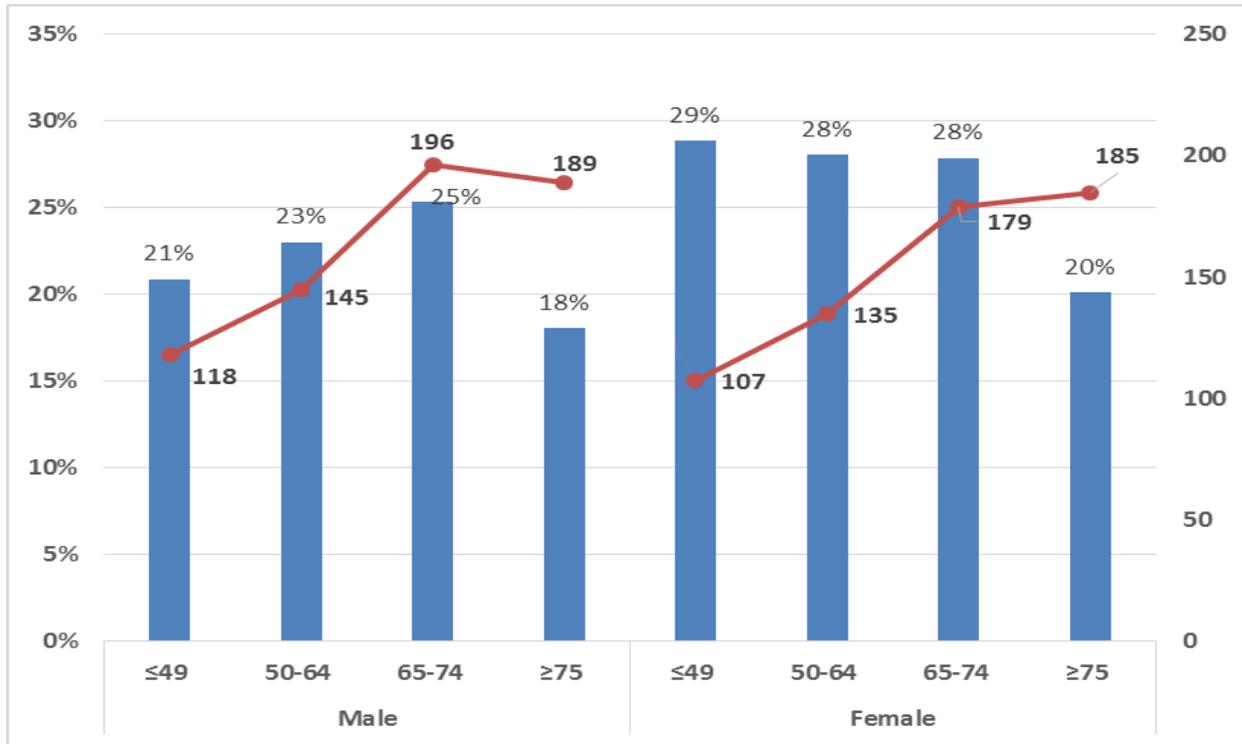
Source: Lewin's analysis of the Current Population Survey Volunteer Supplement (2017).

Exhibit III-13 shows that across age and gender and for both the PWP and the care partners, PD leads to a significant reduction in individuals' ability to perform volunteer work, ranging from a 46% reduction among the SCPs to a 62% reduction among the PWPs. Overall monetary value of lost social productivity is $623 million for PWPs, $341 million for PCPs, and close to $70 million for SCPs.

Exhibit III-13. Estimated social productivity loss due to Parkinson's disease

	PWP		PCP		SCP	
	Average Change in Hours	Total Annual Social Productivity Loss (in Million $s)	Average Change in Hours	Total Annual Social Productivity Loss (in Million $s)	Average Change in Hours	Total Annual Social Productivity Loss (in Million $s)
Males						
≤49 years	9.3 (66%)	1	10.1 (61%)	4	4.7 (42%)	8

	PWP		PCP		SCP	
	Average Change in Hours	Total Annual Social Productivity Loss (in Million $s)	Average Change in Hours	Total Annual Social Productivity Loss (in Million $s)	Average Change in Hours	Total Annual Social Productivity Loss (in Million $s)
50-64 years	6.9 (59%)	49	6.6 (47%)	12	8.2 (56%)	10
65-74 years	7.2 (54%)	165	6.9 (50%)	39	9.9 (54%)	5
≥75 years	11.2 (70%)	133	8.5 (58%)	42	8.0 (65%)	1
Females						
≤49 years	8.1 (67%)	7	6.7 (50%)	10	5.1 (41%)	16
50-64 years	7.6 (56%)	40	7.9 (54%)	65	9.0 (50%)	22
65-74 years	8.1 (53%)	82	8.4 (53%)	124	4.0 (26%)	4
≥75 years	11.7 (73%)	145	9.2 (52%)	45	8.8 (62%)	3
Overall	**8.9 (62%)**	**623**	**8.1 (53%)**	**341**	**6.7 (46%)**	**69**

Source: Lewin's analysis of the Current Population Survey Volunteer Supplement (2017), combined with primary data collected through the PD Impact Survey, and PD prevalence estimated by Lewin.

D. Non-Medical Costs

Disability Income

As shown in **Exhibit III-14**, while around 4% of the PWPs received supplemental security income (SSI), 9% of the PWPs received social security disability insurance (SSDI) or other types of disability income (OTDI). PWPs younger than age 65 are more likely to receive SSDI and OTDI. The overall disability income totals $4.8 billion, with the subgroup aged 50-74 receiving the largest share of the total disability income.

Exhibit III-14. Estimated disability income received by persons with Parkinson's in the past 12 months

	% with SSI in Past 12 Month	Average SSI among those with SSI ($)	% with SSDI in Past 12 Month	Average SSDI among those with SSDI ($)	% with OTDI* in Past 12 Month	Average OTDI among those with OTDI ($)	Total Disability Income (in Million $s)
Males							
≤49 years	8%	6,886	19%	14,171	17%	66,552	35
50-64 years	4%	16,711	34%	20,709	22%	39,937	1,740
65-74 years	5%	17,949	7%	18,578	9%	28,706	1,221
≥75 years	3%	12,788	1%	12,534	8%	24,279	564
Females							
≤49 years	4%	7,700	17%	27,936	13%	30,494	130

	% with SSI in Past 12 Month	Average SSI among those with SSI ($)	% with SSDI in Past 12 Month	Average SSDI among those with SSDI ($)	% with OTDI* in Past 12 Month	Average OTDI among those with OTDI ($)	Total Disability Income (in Million $s)
50-64 years	4%	11,083	27%	15,372	14%	21,661	597
65-74 years	4%	11,118	8%	14,553	4%	19,266	303
≥75 years	5%	8,290	2%	8,384	2%	9,978	168
Overall	**4%**	**13,070**	**9%**	**17,924**	**9%**	**28,468**	**4,760**

Source: Primary data collected through the PD Impact Survey, combined with PD prevalence estimated by Lewin.
*Annual other types of disability income (OTDI)

Other Non-medical Costs

The percentage of PWPs with spending on hiring someone to provide daily care or assistance and the amount spent per-PWP generally increases with age. In total, PWPs age 75 years or older incurred the highest spending acquiring daily care. Overall, $3.8 billion was spent on this cost component. (**Exhibit III-15**).

Exhibit III-15. Estimated formal non-medical care costs due to Parkinson's disease

	% of PWPs Who Hired Someone to Provide Daily Care in the Past 12 Month	Average Cost ($)	Total Cost of Paid Non-Medical Care (in Million $s)
Males			
≤49 years	9%	4,013	0.9
50-64 years	6%	18,831	123
65-74 years	12%	15,887	479
≥75 years	26%	20,107	1,210
Females			
≤49 years	9%	4,977	6.2
50-64 years	6%	6,022	29
65-74 years	11%	18,616	257
≥75 years	33%	24,137	1,744
Overall	**18%**	**20,348**	**3,847**

Source: Primary data collected through the PD Impact Survey, combined with PD prevalence estimated by Lewin.

Exhibit III-16 shows the percentage of PWPs who incurred other non-medical costs. About 26% of PWPs or their family incurred expenses on home modifications (e.g., building a ramp in place of steps to enter/exit home); 10% on purchasing a special vehicle or purchasing/installing special

equipment on a car or other motor vehicles; and 61% had increased transportation cost for reasons such as driving to and from clinics, rehab facilities, visiting PWP who lives in a nursing home, etc. Overall, PWPs and their families spent close to $3.7 billion on the three key components of the non-medical cost categories.

Exhibit III-16. Estimated other non-medical costs due to Parkinson's disease

	Home Modification Cost		Motor Vehicle Related Cost		Increased Transportation Costs		Total Cost (in Million $s)
	% of PWP with the Expense	Average Expense	% of PWP with the Expense	Average Expense	% of PWP with the Expense	Average Expense	
Males							
≤49 years	18%	20,836	9%	7,666	51%	868	12
50-64 years	18%	8,465	6%	8,475	55%	1,065	277
65-74 years	23%	10,827	9%	11,688	59%	754	1,008
≥75 years	31%	7,158	12%	9,231	69%	773	898
Females							
≤49 years	7%	10,560	7%	12,480	64%	803	31
50-64 years	18%	7,988	6%	15,069	56%	765	213
65-74 years	24%	11,717	8%	7,780	55%	803	505
≥75 years	35%	5,564	14%	6,204	66%	893	745
Overall	**26%**	**8,185**	**10%**	**8,964**	**61%**	**826**	**3,689**

Source: Primary data collected through the PD Impact Survey, combined with PD prevalence estimated by Lewin.

E. Total Economic Burden of Parkinson's Disease in 2017

As shown in **Exhibit III-17**, PD is associated with a total excess medical cost of $25.4 billion in 2017 and an average excess cost of $24,439. Because PD prevalence increases by age, the age groups older than 65 represent 82% of total medical cost of PD. Males, although incurring slightly lower per-person cost than female PWPs, do have a higher overall direct medical cost burden, due to the higher prevalence of PD among males. Hospital inpatient care, non-acute institutional care (e.g. SNF, nursing home, hospice), and outpatient care represent the three highest cost categories, followed by prescription medications, physician office visit, and durable medical equipment. The entire Medicare eligible PD population (disabled PWPs under 65 and anyone 65 or older) incurs 90% of the total direct cost burden of PD, with per-person cost slightly higher than those privately insured or those with other insurance or are uninsured.

The non-Hispanic White group represents near 70% of total medical cost, although incurring a lower per-person cost than the other three racial/ethnic groups. However, the estimates by

race/ethnicity should be interpreted carefully because of the following reasons: 1) in every each data source we used for calculating PD prevalence and direct medical cost, there is a subgroup of the study subjects with missing race/ethnicity information; 2) the unweighted raw counts of non-White PWPs in the national surveys such as MEPS and MCBS are very small and often include outliers. A combination of these factors made the estimates for the minority groups less robust than that for the non-Hispanic White group. Additionally, the per-person cost estimates across different race/ethnicity groups are not risk adjusted and therefore may be a result of the differences in underlying population characteristics such as age, gender, and geographic location.

Exhibit III-17. The direct medical cost of Parkinson's disease in 2017 by types of services and population characteristics

	Total Excess Medical Cost due to PD		Mean Excess Cost due to PD ($)
	Cost in Millions	Percentage of the Total	
Age			
≤49	490	2%	29,346
50-64	4,153	16%	22,598
65-74	8,858	35%	23,011
≥75	11,847	47%	26,222
Gender			
Male	13,580	54%	22,838
Female	11,768	46%	26,589
Race/Ethnicity			
Non-Hispanic White	17,280	68%	20,708
Non-Hispanic Black	2,708	11%	35,277
Hispanic	4,661	18%	43,766
Other	699	3%	35,876
Insurance			
Private	1,742	7%	22,671
Medicare	22,793	90%	24,811
Other*	812	3%	19,489
Type of service			
Non-acute Institutional Care	7,144	28.2%	6,888
Hospital Inpatient	7,190	28.4%	6,932
Outpatient	5,506	21.7%	5,308
Physician Office	1,226	4.8%	1,182
Durable Medical Equipment	145	0.6%	140
Prescription Medication	4,137	16.3%	3,988
Overall	**25,348**	**100%**	**24,439**

Source: Lewin analyses of PD prevalence using 2011-2015 Medical Expenditure Panel Survey (MEPS), 2015 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2017; combined with direct medical cost

estimates using 2016 Optum claims, 2015 Medicare Standard Analytical File 5% sample claims, and 2015 Medicare Current Beneficiary Survey (MCBS). *Other includes Medicaid, other insurance, and uninsured.

The estimated total indirect and non-medical costs of PD is $26.5 billion in 2017, with a little less than $20 billion to PWPs and another $6.5 billion to unpaid caregivers. Among the $26.5 billion, total indirect cost is $14.2 billion, non-medical cost $7.5 billion, and $4.8 billion due to disability income received by the PWPs. Future earnings loss due to PD related premature death, earnings loss from reduced employment, and absenteeism are the three largest indirect cost categories for PWPs; and the cost of acquiring daily non-medical care and home modification related expenses represent the largest non-medical costs. Productivity loss due to absenteeism and presentism among the care partners even surpass that of the PWPs. Other disability income is the largest share in the disability income cost component. Average per-person indirect and non-medical costs is $25,558 (PWP and care partner losses combined), with $13,703 due to indirect cost, $7,266 due to non-medical costs, and $4,589 due to disability income. (**Exhibit III-18**).

Exhibit III-18. The indirect and non-medical costs of Parkinson's disease in 2017 by cost component

	Total Indirect and Medical Costs (in Million $s)			Per Capita ($)		
	PWP Loss	Care Partner Loss	PWP & Care Partner	PWP Loss	Care Partner Loss	PWP & Care Partner
Premature Death	2,508	NA	2,508	2,418	NA	2,418
Reduced Employment	1,873	802	2,675	1,806	773	2,579
Absenteeism	1,395	3,655	5,050	1,345	3,524	4,869
Presenteeism	1,263	1,684	2,946	1,217	1,623	2,841
Social Productivity Loss in Volunteer Work	623	410	1,034	601	396	997
Disability Income						
Supplemental security income (SSI)	561	NA	561	541	NA	541
Social security disability insurance (SSDI)	1,677	NA	1,677	1,617	NA	1,617
Other disability income	2,521	NA	2,521	2,431	NA	2,431
Non-Medical Costs						
Paid daily non-medical care	3,847	NA	3,847	3,709	NA	3,709
Home modification	2,232	NA	2,232	2,151	NA	2,151
Motor vehicle modification	931	NA	931	897	NA	897
Other expenses	527	NA	527	508	NA	508
Overall	**19,958**	**6,551**	**26,509**	**19,242**	**6,316**	**25,558**

Source: Lewin analyses of PD Impact Survey data, supplemented with other data sources such as CDC Wonder death records, Bureau of Labor Statistics earnings data; combined with prevalence estimated using 2011-2015 Medical Expenditure Panel Survey (MEPS), 2015 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2017.

IV. Discussion

This new study provides a comprehensive assessment and a deeper understanding of the economic burden of PD in the U.S. in 2017. The total economic burden of PD was $51.9 billion in 2017, including a direct medical cost of $25.4 billion and $26.5 billion in indirect and non-medical costs. These findings show that the true impact of PD has been previously underestimated in the literature.

Another highlight of the study is the Social and Financial Impact of Parkinson's Disease Survey (the PD Impact Survey). This primary survey was specifically designed and administered for this study to deepen the understanding of the full spectrum of PD's impact. The survey was able to collect detailed data on a broad set of indirect and non-medical costs of PD that were previously unavailable, especially the impact of PD on unpaid caregivers. This survey is one of the largest surveys conducted so far on relatively rare neurodegenerative diseases and received a near 5,000 responses from the PD community.

Findings and Discussion of the Economic Burden of PD in 2017

Prevalence: Based on an analysis of the Medical Expenditure Panel Survey (MEPS) and the Medicare Current Beneficiary Survey (MCBS), we found a total of 1.04 million individuals in the U.S. with diagnosed PD in 2017. PD is much more prevalent in the ≥65 population than in the younger population, with the vast majority (89%) of the PWPs being eligible for Medicare coverage. More males than females have PD. PD prevalence rate is more than double among non-Hispanic White compared to other racial/ethnic subgroups. PD prevalence estimated in this study is similar to a more recent study conducted by the Parkinson's Foundation.[7]

Direct medical cost: PD is associated with an excess medical cost of $25.4 billion in 2017, higher than previous U.S. based estimates due to factors that we will discuss below. The vast majority of the medical cost of PD is borne by populations eligible for Medicare coverage (90%), 7% by those with private insurance, and 3% by those in the Other group (including Medicaid, other insured, and uninsured). Average per-person cost was $22,671 and $19,489 for the privately insured and Other group of PWPs <65 years of age, respectively; and $24,811 for the Medicare eligible population with PD (including those <65 due to disability and anyone ≥65 years of age). While hospital inpatient cost is the largest cost driver among the privately insured PWPs (36% of the $1.7 billion for the privately insured), non-acute institutional care (including SNF, nursing home, etc.) is the largest among Medicare eligible beneficiaries with PD (31% of the $22.8 billion for Medicare eligible PWPs); and outpatient care represents the largest share of PD cost among the Other group (38% of the $812 million).

Due to the nature of PD, cost of long-term care has been a concern in the PD community. In this study we defined long-term care more broadly by including cost of nursing homes, SNFs, and hospice for consistency across different data sources and classified all these costs into a common category called "non-acute institutional care". We estimated the total excess cost due to PD in non-acute institutional care to be $7.1 billion (see Exhibit ES-2). A 2015 study[24] found that Medicare alone had approximately 100,000 PWPs who were institutionalized, and the average annual costs of nursing home care was between $82,128 and $92,376 per-person-per-year in 2019.[25] Combining these numbers would result in an annual nursing home care cost of $8-$10 billion for the PWPs

eligible for Medicare. However, this range is the total cost of nursing home care spent for Medicare PWPs, not necessarily the excess cost due to PD for long-term care, because some PWPs would incur long-term care costs, regardless of whether they have PD or not. Hence, the attributed cost for long-term care includes the cost associated with the increase in incidence and the excess cost of long-term care of PWPs compared to otherwise similar individuals.

Another consideration to note about the excess cost of non-acute institutional care due to PD is that although Medicare does not cover cost of nursing home care or longer SNF stays, the MCBS captures all medical expenses paid by Medicare or other non-Medicare payers for those who are dually eligible (e.g. for Medicaid). Therefore, the direct medical costs estimated for the Medicare population in this study should be interpreted as the PD cost paid by all possible sources for those who are eligible for Medicare, not only those paid by the Medicare program. We found that the majority of the PWPs in 2017 were 65 and older and only a little more than 40,000 PWPs younger than 65 were covered by non-private insurance such as Medicaid, TRICARE, or were uninsured (see the "Other" group in Exhibit ES-1). Therefore, the direct cost of PD for Medicaid beneficiaries who are older than 65, and thus dually eligible for Medicare, are already captured by the cost estimates for the Medicare eligible population. For the ~40,000 PWPs younger than 65, the cost imputation based on the Optum claims data also captures all types of services, including long-term care.

Indirect and non-medical costs: The estimated total indirect and non-medical costs of PD is $26.5 billion in 2017, with near $20 billion to persons with PD and another $6.6 billion to unpaid care partners. Average indirect and non-medical cost per PWP is $19,242 for PWP only and $25,558 for PWP combined with caregiver burden. Total indirect cost (PWP and caregiver combined) is $14.2 billion with absenteeism cost being the largest share, followed by presenteeism cost and reduced employment related earnings loss. Total non-medical cost is $7.5 billion with the paid non-medical daily care being the largest share, followed by home modification cost. PD associated disability income, including SSI, SSDI, and other disability income, is approximately 4.8 billion, although considered transfer cost and not a direct economic loss.

Comparison with other PD burden estimates and cost of other neurologic diseases in the literature:

The direct medical cost, and indirect & non-medical costs of PD estimated in this study are higher than previous U.S. based studies of PD burden.[4,5,6] However studies compared have significantly different data sources, methods, and include different cost components of interest. Therefore any comparison between the findings of this new study and any previous literature should consider these differences.

Exhibit IV-1: Comparison of the current study with PD burden estimates in the literature

U.S. PD Burden Study	Prevalence	Direct Cost	Indirect & Non-Medical Costs
Current study (2017 cost)	1,040,000	Total: $25,348 M Per capita: $24,439 (in 2017 $s)	Total: $26,509 M Per capita: $25,558 (in 2017 $s)

U.S. PD Burden Study	Prevalence	Direct Cost	Indirect & Non-Medical Costs
Kowal 2013 (2010 cost)	630,000	Total: $8,064 M Per capita: $12,805 ($15,749 in 2017 $s)	Total: $6,327 M Per capita: $10,046 ($12,355 in 2017 $s)
O'Brien 2009 (2007 cost)	500,000	Total: $6,246 M Per capita: $12,491 ($15,823 in 2017 $s)	Total: $4,568 M Per capita:$9,135 ($11,572 in 2017 $s)
Huse 2006 (2003 cost)	645,000	Total: $6,675 M Per capita: $10,349 ($15,654 in 2017$s)	Total: $16,335 M Per capita: $25,326 ($38,308 in 2017 $s)

Source: Literature Review

As shown in **Exhibit IV-1** above, the PD prevalence estimated in this new study is significantly higher than the three previous comprehensive PD burden studies identified in the literature. While our prevalence estimates may represent a real PD prevalence growth from earlier years to 2017, the difference between our findings and these earlier studies are also driven by methodological differences. Specifically, the Kowal study reported a PD prevalence of 647,000 in 2010 that were estimated using 2003-2008 MEPS data combined with the 2004 National Nursing Home Survey (NNHS) for the institutionalized population.[4] Our study used the 2011-2015 MEPS data combined with the 2015 MCBS, which is likely to represent the Medicare beneficiary population better than the MEPS data or the NNHS data. The O'Brien study conducted their PD burden estimates based on an assumption of PD prevalence of roughly 500,000 in 2007.[5] The Huse study applied the PD prevalence rates estimated form the EUROPARKINSON study to the 2003 U.S. population age ≥65 and used the age distribution from an United Kingdom based PD survey to project to US <65 population to derive PD prevalence. Their estimates yielded a total of 849,000 PWPs, which was then downward adjusted by 24% to remove any potential cases of undiagnosed PD, which were included in the EUROPARKINSON study.[6]

The current study and the Kowal study both used one diagnosis code of PD to identify PWPs in the MEPS data. Although it is plausible that relying on one diagnosis code for PWP identification may have included certain false positive cases, it is also possible that some false negative cases may have been left out due to misdiagnosis of PD as other conditions. The extent to which the prevalence has been over- or under-estimated is unknown. A recent prevalence estimate by the Parkinson's Foundation, using data sources such as electronic medical records has shown to be similar to the estimates of the current study.[7]

Our total direct medical cost estimate is much higher than the previous burden estimates mostly because of our significantly higher prevalence estimate. However, on a per-capita basis, our direct medical cost per PWP is also higher than the previous estimates even when those cost estimates were inflated to 2017 dollar values. The Kowal study estimated a per-capita direct medical cost of $12,805 ($15,749 in 2017 $s).[4] They estimated the medical cost of PD using data sources including the National Ambulatory Medical Care Survey (NAMCS), the National Hospital Ambulatory Medical Care Survey (NHAMCS), National Inpatient Sample (NIS), and National Home and Hospice Care Survey (NHHCS). Based on reviews of a physician, they attributed 100% of the cost on healthcare encounter data where PD is the primary diagnosis PD, and only a certain percentage

of the costs on encounters where PD is secondary diagnosis to PD (e.g. 27% of physician office visit related cost).[4] The O'Brien study used data sources such as the NAMCS, the National Health Interview Survey (NHIS), the Minnesota long-term care database, Medicare Physician and Lab Fee Schedules, Average Wholesale Price for prescription drugs, and supplementary data from the literature to estimate the direct medical cost of PD.[5] Both the Kowal and O'Brien studies relied heavily on national survey data to estimate the medical cost of PD, which is likely an important factor in their estimates being smaller than our estimates. It is found that survey based healthcare utilization and medical cost analyses tend to underestimate the true level of health services use because surveys are less likely to include individuals whose disease is severe or those that are high cost outliers.[26] The cost imputation methods as often used in survey data is likely another source that would smooth the cost variations.

The Kowal study and the O'Brien study both included fewer indirect and non-medical cost categories than the current study. The Kowal study mainly relied on the NHIS and a regression based approach to estimate the cost of reduced employment due to PD, absenteeism, income loss, and SSI payments by comparing individuals with neurologic disorders (NHIS does not have an indicator variable for PD) and those without the neurologic disorder indicators, controlling for individual characteristics such as age, gender, race/ethnicity, education level, etc. The Kowal study also estimated cost of formal non-medical care using the Metlife Survey of Adult Day Services. The O'Brien study estimated absenteeism cost of PD by obtaining days missed from work by PWPs and caregivers from the literature and multiplied with average wages and earnings data from the BLS. They also estimated the cost of Social Security death benefits and funeral expenses and other out-of-pocket expenses for PD related deaths. While our indirect and non-medical costs include several more cost components, we do not include the cost of income loss (as it would double count the reduced employment costs in our analysis) nor do we include the cost of Social Security death benefits or funeral costs.

The Huse study, by the nature of the data source used, should be the most comparable to ours in the sense that both have mainly replied on claims data to estimate direct medical costs and both estimated PD excess cost by comparing PWPs with matched comparison groups. However, one major difference is that the Huse study relied on the MarketScan claims data while we used the Optum claims data for the privately insured as well as the Medicare 5% claims data and the MCBS data for the Medicare population. The Huse study mentioned that the MarketScan data they were using included claims for the privately and Medicaid insured, but it is unclear if they also included Medicare covered beneficiaries. It is also unclear if the Medicaid claims in the MarketScan data used were for the fee-for-service beneficiaries or for the Medicaid Managed Care beneficiaries. If latter, it is possible that Managed Care beneficiaries are healthier than the fee-for-service population and hence would incur smaller costs. It is also worth pointing out that the Huse study estimated the annual direct medical cost of PD by averaging the PD excess costs in the ≤3 years of follow up period post the index date (the date of the first PD diagnoses in the continuously covered enrollment period during which a PWP was identified. It could include both new and established PWPs). This may have been another reason for the medical cost being different in the Huse study from our estimates. By excluding the period before diagnosis (for the new PWP share of the Huse study sample), the cost included in the Huse study may be lower than if the pre-index period was included in the cost estimates.

The Huse study did not conduct original indirect and non-medical cost estimates. Rather they cited such cost estimates from the Whetten-Goldstein study that estimated PD burden based on a comprehensive survey – the Duke Survey study.[11] This study collected data from PWPs receiving care from providers near the Duke university hospital and captured cost components that are as comprehensive as ours but are based on a much smaller survey sample (n=109). This study provided a somewhat higher per-capita total indirect and non-medical cost estimates than ours (>$30,000 in 2017 $s as opposed to our estimate of $25,558 in 2017).

Several studies focused on the direct medical cost of PD only. A 2016 JAMA study[27] based on many different data sources (e.g. NAMCS, NHAMCS, the MarketScan claims data, and the 2004 National Nursing Home Survey) estimated that the total direct medical cost of PD was $4.9 billion in 2013 ($5.5 B in 2017) and 50.5% ($2.5 billion in 2013 and $2.8 billion in 2017) of this amount was for PD related nursing home cost. Given that this study was simultaneously modeling the direct cost of more than 150 diseases and accounted for the cost overlapping that were due to multiple comorbidities, their cost estimates are understandably smaller than our estimates for PD only.

Another study, Noyes 2006[28], used the 1992-2000 MCBS data and found that after adjusting for other factors (i.e. sociodemographic characteristics such as age, gender, race, income; and comorbidities including cardiovascular, musculoskeletal, reproductive, psychiatric, pulmonary, metabolic, dermatological, gastrointestinal, renal, stroke), PWPs had higher annual health care expenses than beneficiaries without PD ($18,528 vs. $10,818; P<0.001). After inflating to 2017 dollars, these become $28,866 and $16,854 respectively. In addition to the fact that this study was done using much earlier data, there are two other noticeable differences between this study and our estimates: 1. In the Noyes study, the comparison between PD vs. non-PD was adjusting for both demographic factors and comorbidities, while our study only adjusted for age, sex, race/ethnicity, and insurance coverage based on our belief that PD affects the whole body and may increase healthcare utilization and spending for comorbidities. 2. The Noyes study relied solely on the MCBS data to estimate utilization and cost, while we relied on MCBS for prescription drug cost and log-term care cost but the Medicare claims data for all other types of services. As compared to the claims data, analyses of healthcare utilization and costs based on survey data such as the MCBS will likely underestimate the true cost of a disease, due to much small sample sizes, data imputations, and the reduced likelihood to exclude cost outliers.

A more recent study (Mantri 2018[29]) based on Medicare Part A & B claims data found that on average, $20,142 Medicare dollars were spent per beneficiary with PD. This is consistent with our estimated average of Part A & B cost of $19,365 per Medicare beneficiary with PD based on the Medicare 5% claims alone. However, our total per-capita cost for the Medicare eligible population with PD also included the costs of non-acute institutional care and prescription drug costs estimated from the MCBS.

There are several other U.S. based studies that estimated the medical costs associated with PD, however, these studies either focused on cost of newly diagnosed PD (e.g. Johnson 2011**Error! Bookmark not defined.**) or a particular cost component such as home health care (e.g. Bhattacharjee 2013[30]) and are therefore not comparable with our estimates.

International studies vary significantly in the burden estimates for PD. With studies in the developing countries estimating a much smaller per-capita cost of PD and the European countries such as Germany having higher estimates.[29,31] A very recent study conducted by Takeda researchers in Japan using the Japanese National Health and Wellness Survey estimated a direct medical cost of $30,948 ($37,994 PD vs. $7,046 non-PD) and an indirect cost of $16,465 ($25,356 vs. $8,891).[32] It also showed an almost 6.0-fold and 2.5-fold higher absenteeism and presenteeism costs comparing PD with non-PD.[32] However, these international studies are not comparable to the current study due to differences in study design and analytical approaches, cost categories investigated, definitions of cost measures, as well as some systematic differences such as health insurance practice, quality and efficiencies of healthcare delivery, and characteristics of the PD population studied.

The total (direct and indirect) cost estimates from our study are similar to other chronic, disabling diseases in the U.S. A study in 2006 on multiple sclerosis estimated that the average costs are about $47,215 per-patient per-year. Of these, 53% were for direct medical and non-medical costs, 37% for productivity losses, and 10% for informal care.[33] It was also found that the additional cost of annual informal caregiving per person with severe dementia (e.g., due to Alzheimer's) was $17,701.[34] 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), $50,952 for Duchenne muscular dystrophy (DMD), and $32,236 for myotonic dystrophy (DM).[35]

Study Limitations

A key limitation of the study is the omission of undiagnosed PD. Many individuals with early PD symptoms may regard these symptoms as part of 'normal aging', and thus do not present to their doctors and, hence, may lead to PD being underdiagnosed. In this study, we focus on the diagnosed PD, due to its significantly higher economic burden and less controversial approach in case identification.

A second limitation of the study is the use of private insurance claims to impute cost for the non-private, non-Medicare covered PD population that is collectively referred as Other. Due to the constraints in obtaining other payer-specific data, and an attempt to use the MEPS data for this portion of the PD population was unable to identify a sufficient sample (<20 unweighted PWPs were identified), we used the Optum data to impute the costs by age and gender for the non-private, non-Medicare covered population or those uninsured. To ensure any intrinsic cost differences between the privately insured and the non-private, non-Medicare population are accounted for, we used the MEPS data and regression analysis to estimate the cost ratios between the Other group and the privately insured (regardless of their PD status) and used the ratio to adjust the imputed costs.

Due to the use of the MEPS and MCBS data for PD prevalence and the use of MCBS to estimate the long-term care cost and prescription drug cost for the Medicare population, certain population strata specific analysis (e.g. by race/ethnicity) in this study encountered the small sample size issue. When sample sizes are too small for valid analysis, we aggregated the analysis to larger subgroups, to provide more robust prevalence and cost estimates. However, certain strata-specific estimates may still be subjected to small sample size and outlier issues.

A final limitation of the study is that families that responded to the survey may not be a completely randomized group. The PD Impact Survey was administered to a convenience sample rather than a true random sample of the PD population, due to lack of access to the sampling frame. However, the 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 took some time to complete, so it might be possible that the families most affected by the disease severity were less likely to return the survey, although it was reassuring to see that more than 7% of our sample were from families where the PWP were requiring round-the-clock care or were institutionalized and therefore providing us with sufficient sample for subgroup analysis. As with any other survey research, indirect and non-medical costs estimated based on self-reported data may be subject to recall bias.

Conclusion:

This new study provides a comprehensive evaluation of the current and future impact of PD 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 PD of more than $51.9 billion in 2017, including $25.4 in direct medical cost and $26.5 billion in indirect and non-medical costs. This estimate is much higher than previously understood due to both a higher prevalence estimate and a higher per-capita cost (per-capita direct medical cost is $24,439 and indirect and non-medical cost is $25,558 when PWP and care partner losses are combined). PD prevalence estimated using nationally representative surveys for younger and elderly U.S populations revealed a much higher prevalence than previous literature. However, these estimates are close to the most recent estimates by the Parkinson's Foundation. Our findings show that PD significantly affects payers, employers, individuals with the disease, and unpaid care partners. The Medicare program bears the largest share of excess medical cost, as most PWPs are over age 65, while employers experience significant productivity loss from those PWPs who are in the labor force, the government spends more on providing disability income, and PWPs and their care partners significantly lose the ability to participate in labor market or volunteer activities.

The findings of this study help underscore the burden of PD 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, disease management by specialists, work-site support, employment and occupational training, and preventive or treatment measures to reduce PD onset and delay PD progression. The findings will inform the decision making in PD related health resource investment and prioritization.

Appendix A: Comparison Group Characteristics

Exhibit A-1. Comparison of age, gender, & race/ethnicity between Parkinson's disease and comparison groups by data source

		PD		Comparison	
		N	**Percent**	**N**	**Percent**
Optum Claims Data					
Gender	Male	1,575	60.5%	15,750	60.5%
	Female	1,029	39.5%	10,290	39.5%
Age Group	≤49	408	15.7%	4,080	15.7%
	50-64	2,196	84.3%	21,960	84.3%
	65-74	N/A	N/A	N/A	N/A
	≥75	N/A	N/A	N/A	N/A
Race/Ethnicity	NH White	1,803	69.2%	18,030	69.2%
	NH Black	95	3.7%	950	3.7%
	Hispanic	176	6.8%	1,760	6.8%
	Other	246	9.4%	2,460	9.4%
	Unknown	284	10.9%	2,840	10.9%
Medicare 5%					
Gender	Male	12,102	54.0%	121,020	54.0%
	Female	10,308	46.0%	103,080	46.0%
Age Group	≤49	209	0.9%	2,090	0.9%
	50-64	1,654	7.4%	16,540	7.4%
	65-74	7,406	33.1%	74,060	33.1%
	≥75	13,141	58.6%	131,410	58.6%
Race/Ethnicity	NH White	19,579	87.4%	195,790	87.4%
	NH Black	1,311	5.9%	13,110	5.9%
	Hispanic	418	1.9%	4,180	1.9%
	Other	888	4.0%	8,880	4.0%
	Unknown	214	1.0%	2,140	1.0%
Medicare Current Beneficiary Survey					
Gender	Male	97	55.1%	970	55.1%
	Female	79	44.9%	790	44.9%
Age Group	≤49	6	3.4%	60	3.4%
	50-64	10	5.7%	100	5.7%
	65-74	45	25.6%	450	25.6%
	≥75	115	65.3%	1,150	65.3%
Race/Ethnicity	NH White	144	81.8%	1,140	81.8%
	NH Black	11	6.3%	110	6.3%
	Hispanic	19	10.8%	190	10.8%
	Other	2	1.1%	20	1.1%
	Unknown	N/A	N/A	N/A	N/A

Source: Lewin analyses of 2016 Optum claims, 2015 Medicare Standard Analytical File 5% sample claims, and 2015 Medicare Current Beneficiary Survey (MCBS).

Exhibit A-2. Comparison of per-capita cost between PD and comparison groups, by age, gender, and insurance (in 2017 $s)

Insurance	Age Group	Gender	Per-PWP ($)	Per-Comparison Person ($)
Private	≤49	Male	-	-
		Female	-	-
	50-64	Male	32,539	9,062
		Female	31,428	9,275
Medicare	<=49	Male	44,243	13,737
		Female	43,550	15,409
	50-64	Male	43,508	19,142
		Female	46,188	19,657
	65-74	Male	33,011	10,204
		Female	34,476	11,057
	≥75	Male	36,643	13,546
		Female	44,076	14,581
Other	≤49	Male	-	-
		Female	33,121	3,434
	50-64	Male	23,225	6,468
		Female	22,432	6,620

Source: Lewin analyses of PD prevalence using 2011-2015 Medical Expenditure Panel Survey (MEPS), 2015 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2017; combined with direct medical cost estimates using 2016 Optum claims, 2015 Medicare Standard Analytical File 5% sample claims, and 2015 MCBS.

Appendix B: Comparison of Death Rates

Exhibit B-1. Comparison of death rates derived from CDC Wonder and Medicare 5% data for the Parkinson's disease and Non-Parkinson's elderly population (2017)

Gender/Age Group	PD Wonder Death Rate	PD Claims Death Rate	Non-PD Wonder Death Rate	Non-PD Claims Death Rate
Males				
65-74	1.81%	7.75%	2.28%	2.48%
75+	9.84%	18.17%	7.75%	7.87%
Females				
65-74	1.77%	5.76%	1.49%	1.61%
75+	7.09%	15.98%	6.93%	7.29%

Source: Lewin analyses of 2014-2016 CDC Wonder and 2017 Medicare 5% claims data.

Appendix C: Survey Sample Characteristics

Exhibit C-1. Education attainment and marital status of the persons with Parkinson's and unpaid care partners

			Unweighted			Weighted		
			PWP	PCP	SCP	PWP	PCP	SCP
All			4,548	2,677	716	1,037,211	648,185	190,936
Education Attainment	High School or Less	N	484	310	96	130,986	74,551	23,372
		%	10.6	11.6	13.4	12.6	11.5	12.2
	Associate's Degree or Some College	N	1,094	742	187	250,529	180,497	47,419
		%	24.1	27.7	26.1	24.2	27.8	24.8
	Bachelor's Degree	N	1,310	785	239	283,142	187,873	66,849
		%	28.8	29.3	33.4	27.3	29.0	35.0
	Master's Degree	N	1,100	603	123	244,438	146,581	34,638
		%	24.2	22.5	17.2	23.6	22.6	18.1
	PhD Degree	N	535	220	31	123,214	54,532	8,147
		%	11.8	8.2	4.3	11.9	8.4	4.3
	Prefer not to say / Do not know	N	25	17	40	4,903	4,152	10,510
		%	0.5	0.6	5.6	0.5	0.6	5.5
Marital Status	Married/Living With Partner	N	3,666	2,457	339	810,397	589,321	98,972
		%	80.6	91.8	47.3	78.1	90.9	51.8
	Divorced/Separated	N	419	82	100	94,179	20,554	28,174
		%	9.2	3.1	14.0	9.1	3.2	14.8
	Widowed	N	272	33	20	96,623	8,191	4,499
		%	6.0	1.2	2.8	9.3	1.3	2.4
	Never Married	N	149	75	207	28,846	23,071	45,934
		%	3.3	2.8	28.9	2.8	3.6	24.1
	Prefer not to say / Do not know	N	33	30	50	7,166	7,048	13,358
		%	0.7	1.1	7.0	0.7	1.1	7.0

Source: Primary data collected through the PD Impact Survey

Exhibit C-2. Total individual earnings in the most recent tax year

		Unweighted				Weighted			
		PWP	PCP	SCP	Household	PWP	PCP	SCP	Household
	Total	4,548	2,677	716	4,280	1,037,211	655,720	196,660	961,621
< $25,000	N	1,241	826	189	539	318,451	207,202	46,010	150,141
	%	27.3	30.9	26.4	12.6	30.7	31.6	23.4	15.6
$25,000-$50,000	N	986	546	130	671	230,025	136,718	35,469	166,724
	%	21.7	20.4	18.2	15.7	22.2	20.9	18.0	17.3

		Unweighted				Weighted			
		PWP	PCP	SCP	Household	PWP	PCP	SCP	Household
$50,000-$75,000	N	634	372	82	635	135,989	81,920	23,930	143,261
	%	13.9	13.9	11.5	14.8	13.1	12.5	12.2	14.9
$75,000-$100,000	N	453	234	54	588	87,832	48,839	15,547	121,464
	%	10.0	8.7	7.5	13.7	8.5	7.4	7.9	12.6
$100,000-$125,000	N	219	97	35	388	42,934	23,173	9,813	80,757
	%	4.8	3.6	4.9	9.1	4.1	3.5	5.0	8.4
$125,000-$150,000	N	157	77	10	278	30,125	16,167	2,869	53,753
	%	3.5	2.9	1.4	6.5	2.9	2.5	1.5	5.6
$150,000-$175,000	N	94	38	10	187	16,580	8,749	2,538	35,056
	%	2.1	1.4	1.4	4.4	1.6	1.3	1.3	3.6
$175,000-$200,000	N	58	29	8	136	8,749	6,354	2,957	23,590
	%	1.3	1.1	1.1	3.2	0.8	1.0	1.5	2.5
>$200,000	N	159	65	12	290	26,667	14,321	3,888	44,702
	%	3.5	2.4	1.7	6.8	2.6	2.2	2.0	4.6
Prefer not to say	N	547	393	186	568	139,861	112,278	53,639	142,173
	%	12.0	14.7	26.0	13.3	13.5	17.1	27.3	14.8

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 PWP, and excludes co-residents who are financially independent and all paid care partners who are not family members.

Exhibit C-3. Symptom severity for persons with Parkinson's

		Unweighted		Weighted	
		Frequency	Percent	Frequency	Percent
Total		4,548	100	1,037,211	100
Slowed movement	Did not experience	393	8.6	88,159	8.5
	Mild	1,824	40.1	376,662	36.1
	Moderate	1,689	37.1	381,243	36.8
	Severe	642	14.1	191,148	18.4
Tremors	Did not experience	805	17.7	192,225	18.5
	Mild	2,198	48.3	482,086	46.5
	Moderate	1,304	28.7	298,617	28.8
	Severe	241	5.3	64,283	6.2
Poor balance and condition	Did not experience	550	12.1	111,858	10.8
	Mild	1,823	40.1	380,087	36.7
	Moderate	1,432	31.5	328,915	31.7
	Severe	743	16.3	216,351	20.9
Trouble speaking	Did not experience	1,431	31.5	308,375	29.7
	Mild	1,768	38.9	386,077	37.2

		Unweighted		Weighted	
		Frequency	Percent	Frequency	Percent
	Moderate	926	20.4	225,869	21.8
	Severe	423	9.3	116,891	11.3
Trouble writing	Did not experience	727	16.0	150,450	14.5
	Mild	1,589	34.9	338,789	32.7
	Moderate	1,256	27.6	287,281	27.7
	Severe	976	21.5	260,691	25.1
Urinary issues such as urinary urgency or loss of bladder control	Did not experience	1,159	25.5	231,766	22.3
	Mild	1,557	34.2	335,248	32.3
	Moderate	1,231	27.1	294,431	28.4
	Severe	601	13.2	175,767	17.0
Gastrointestinal issues such as constipation or irritable bowel syndrome	Did not experience	1,090	24.0	229,996	22.2
	Mild	1,510	33.2	324,766	31.3
	Moderate	1,352	29.7	320,443	30.9
	Severe	596	13.1	162,006	15.6
Sleep issues (such as trouble falling asleep, staying asleep, abnormal dreams, etc.)	Did not experience	609	13.4	142,961	13.8
	Mild	1,535	33.8	349,520	33.7
	Moderate	1,617	35.6	360,299	34.7
	Severe	787	17.3	184,430	17.8
Fatigue and loss of energy	Did not experience	339	7.5	69,967	6.7
	Mild	1,596	35.1	347,592	33.5
	Moderate	1,791	39.4	406,927	39.2
	Severe	822	18.1	212,726	205
Difficulty with concentrating	Did not experience	1,055	23.2	228,102	22.0
	Mild	1,872	41.2	401,796	38.7
	Moderate	1,140	25.1	268,185	25.9
	Severe	481	10.6	139,128	13.4
Difficulty with memorizing or recalling information	Did not experience	1,064	23.4	220,666	21.3
	Mild	1,826	40.2	394,462	38.0
	Moderate	1,169	25.7	282,816	27.3
	Severe	489	10.8	139,268	13.4
Difficulty with understanding requirements to complete complex tasks	Did not experience	1,817	40.0	379,370	36.6
	Mild	1,447	31.8	322,904	31.1
	Moderate	796	17.5	193,510	18.7
	Severe	488	10.7	141,428	13.6
Difficulty with swallowing	Did not experience	1,967	43.3	419,909	40.5
	Mild	1,750	38.5	394,858	38.1
	Moderate	609	13.4	158,092	15.2
	Severe	222	4.9	64,353	6.2

		Unweighted		Weighted	
		Frequency	Percent	Frequency	Percent
Vision problems	Did not experience	1,984	43.6	431,679	41.6
	Mild	1,643	36.1	363,118	35.0
	Moderate	697	15.3	175,726	16.9
	Severe	224	4.9	66,688	6.4
Pain	Did not experience	1,505	33.1	357,529	34.5
	Mild	1,593	35.0	350,636	33.8
	Moderate	1,095	24.1	246,602	23.9
	Severe	355	7.8	82,445	8.0

Source: Primary data collected through the PD Impact Survey

Exhibit C-4. Presence of cognitive decline or mental health conditions among persons with Parkinson's

Condition	Unweighted		Weighted	
	Frequency	Percent	Frequency	Percent
N	4,548		1,037,211	
None	2,106	46.3	461,095	44.5
Any of the below conditions	2,442	53.7	576,116	55.5
Alzheimer's disease	39	0.86	12,787	1.2
Dementia	427	9.4	127,560	12.3
Bipolar disorder	94	2.1	22,188	2.1
Schizophrenia	15	0.33	4,477	0.43
Hallucinations or delusions	554	12.2	151,096	14.6
Depression	1,557	34.2	354,781	34.2
Anxiety	1,516	33.3	344,018	33.2
Apathy (e.g., a lack of interest or enthusiasm)	727	16.0	172,617	16.6
Other kind of psychotic disorders	60	1.3	13,541	1.3
Other personality or behavioral disorders	149	3.3	34,165	3.3

Source: Primary data collected through the PD Impact Survey

Exhibit C-5. Weeks the persons with Parkinson's relied on a walking device in the past 12 months

	Walkers	Wheelchairs	Canes	Scooters
Unweighted				
N	4,548	4,548	4,548	4,548
n>0	1,141	814	1,091	216

	Walkers	Wheelchairs	Canes	Scooters
Mean(weeks)	18.4	10.1	16.8	2.3
Std	22.0	18.4	21.3	9.3
Min	0	0	0	0
Max	52	52	52	52
Weighted				
N	1,037,211	1,037,211	1,037,211	1,037,211
n>0	325,994	245,951	264,161	55,553
Mean(weeks)	20.8	12.4	15.7	2.2
Std	22.6	19.8	21.2	9.1
Min	0	0	0	0
Max	52	52	52	52

Source: Primary data collected through the PD Impact Survey

Exhibit C-6. Percentage of persons with Parkinson's that experienced the OFF state in the past 12 months and the number of waking hours in a typical day in the OFF state

	Unweighted		Weighted	
	Frequency	Percent	Frequency	Percent
Total	**4,548**	**100**	**1,037,211**	**100**
Do not know	368	8.1	100,909	9.7
No	1,204	26.5	281,354	27.1
Yes	2,976	65.4	654,948	63.2
Less than 1 hour	566	19.0	125,151	19.1
Between 1-2 hours	932	31.3	201,748	30.8
Between 2-3 hours	668	22.5	142,536	21.8
Between 3-4 hours	436	14.7	97,716	14.9
Greater than 4 hours	374	12.6	87,797	13.4

Source: Primary data collected through the PD Impact Survey

Exhibit C-7. Percentage of persons with Parkinson's that experienced dyskinesia in the Past 12 Months and the number of waking hours in a typical day in a dyskinesia state

	Unweighted		Weighted	
	Frequency	Percent	Frequency	Percent
Total	4,548	100	1,037,211	100
Do not know	357	7.9	88,531	8.5
No	2,617	57.5	596,789	57.5
Yes	1,574	34.6	351,891	33.9
Less than 1 hour	498	31.6	498	31.1
Between 1-2 hours	494	31.4	106,593	30.3
Between 2-3 hours	253	16.1	57,953	16.5

	Unweighted		Weighted	
	Frequency	**Percent**	**Frequency**	**Percent**
Between 3-4 hours	138	8.8	34,775	9.9
Greater than 4 hours	191	12.1	43,318	12.3

Source: Primary data collected through the PD Impact Survey

Exhibit C-8. Percentage of persons with Parkinson's ever received any type of device-assisted therapy

Condition	Unweighted		Weighted	
	Frequency	**Percent**	**Frequency**	**Percent**
N	4,548	100	1,037,211	100
Don't know	30	0.66	8,145	0.79
None of the above	3,453	75.9	803,371	77.5
Any Device Assisted Therapy	1,055	23.2	223,747	21.6
Deep Brain Stimulation (surgical procedure used to address tremor and other PD symptoms)	520	11.4	106,171	10.2
Duopa or Levodopa-Carbidopa Intestinal Gels (a non-oral Levodopa medication that is delivered continuously into the intestine)	127	2.8	30,410	2.9
Apomorphine Infusion (a pen or pump-like, injectable device used to deliver medication to address when the medication is "wearing off," or when Levodopa medication is no longer working)	46	1.0	10,800	1.0
Neupro Patch	507	11.2	107,143	10.3

Source: Primary data collected through the PD Impact Survey

Appendix D: Prevalence of Parkinson's Disease by State

Exhibit D-1. Prevalence of Parkinson's disease by state in 2017

State	Population	Number of Individuals with Diagnosed PD	PD Prevalence (Per-1000 population)
Alabama	4,899,211	16,203	3.31
Alaska	724,566	1,806	2.49
Arizona	7,022,372	23,524	3.35
Arkansas	2,984,033	10,012	3.36
California	40,111,105	116,902	2.91
Colorado	5,594,422	16,452	2.94
Connecticut	3,625,168	12,348	3.41
Delaware	962,489	3,405	3.54
District of Columbia	698,042	1,951	2.79
Florida	20,902,734	80,727	3.86
Georgia	10,445,517	27,922	2.67
Hawaii	1,436,510	5,002	3.48
Idaho	1,700,266	5,271	3.1
Illinois	12,811,601	40,544	3.16
Indiana	6,584,787	20,721	3.15
Iowa	3,142,618	10,563	3.36
Kansas	2,907,501	9,014	3.1
Kentucky	4,437,408	14,462	3.26
Louisiana	4,646,455	13,777	2.97
Maine	1,334,992	5,136	3.85
Maryland	6,030,517	18,949	3.14
Massachusetts	6,880,584	21,625	3.14
Michigan	10,019,300	33,502	3.34
Minnesota	5,511,150	18,627	3.38
Mississippi	2,989,236	9,104	3.05
Missouri	5,963,230	21,024	3.53
Montana	1,047,225	4,020	3.84
Nebraska	1,900,122	5,954	3.13
Nevada	2,996,329	9,689	3.23
New Hampshire	1,332,110	4,913	3.69
New Jersey	9,010,924	29,705	3.3
New Mexico	2,094,596	6,607	3.15
New York	19,826,059	65,334	3.3
North Carolina	10,221,421	33,729	3.3
North Dakota	758,933	2,346	3.09
Ohio	11,610,385	37,173	3.2
Oklahoma	3,988,237	12,720	3.19

State	Population	Number of Individuals with Diagnosed PD	PD Prevalence (Per-1000 population)
Oregon	4,189,659	13,926	3.32
Pennsylvania	12,722,692	46,374	3.64
Rhode Island	1,070,284	3,741	3.5
South Carolina	4,975,915	17,288	3.47
South Dakota	867,806	3,193	3.68
Tennessee	6,761,680	22,713	3.36
Texas	28,245,172	72,588	2.57
Utah	3,122,764	7,301	2.34
Vermont	629,017	2,394	3.81
Virginia	8,305,895	24,214	2.92
Washington	7,422,917	23,597	3.18
West Virginia	1,831,974	6,885	3.76
Wisconsin	5,842,856	20,486	3.51
Wyoming	578,389	1,752	3.03
U.S. Total	325,719,172	1,037,211	3.18

Source: Lewin analyses of PD prevalence using 2011-2015 Medical Expenditure Panel Survey (MEPS), 2015 Medicare Current Beneficiary Survey (MCBS), and Census population projection for each state in 2017. National PD prevalence rates were extrapolated to state population by age, gender, and race/ethnicity.

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