

Economic Burden of Parkinson's and Atypical Parkinsonism in the United States

Full Study Report

Final Report

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



Prepared for: **The Michael J. Fox Foundation for Parkinson's Research**

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

February 17, 2026

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Research (MJFF)**

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The Lewin Group is part of Optum Serve and an affiliate of UnitedHealth Group (UHG). Both Optum Serve and UHG recognize that the value of The Lewin Group (Lewin) is its ability to provide independent, objective analysis of health care trends and policies. The impartiality and integrity of Lewin's work is core to what we do. Neither Optum Serve nor UHG or its other subsidiaries review the work products of Lewin. Lewin operates with editorial independence and provides its clients with the very best expert and impartial health care and human services policy research and consulting services.

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Acronyms

Table of Acronyms
2017 PD Impact Survey: Lewin's 2017 Financial and Social Impact Survey
2024 PD and Related Disorders Impact Survey: Lewin's 2024 Financial and Social Impact of Parkinson's Disease and Parkinson's Related Disorders
AP NOS: Parkinsonism not otherwise specified as indicated by ICD-10 G20.C
AP: Atypical Parkinsonism
CBD/S: Corticobasal Degeneration/Syndrome
CDC WONDER: Centers for Disease Control and Prevention Wide-ranging ONline Data for Epidemiology Research
CMS: Centers for Medicare & Medicaid Services
COVID-19: Coronavirus Disease 2019
CPI: Consumer Price Index
DLB: Dementia with Lewy Bodies
dNHI: Optum de-identified Normative Health Information
Dx: Diagnosis
GLP-1: glucagon-like peptide-1
ICD-10: International Classification of Diseases 10 th Revision
ICD-9: International Classification of Diseases 9th Revision
IP: Inpatient
MA: Medicare Advantage
MCBS: Medicare Current Beneficiary Survey
Medicare SAF: Medicare Standard Analytic File
MEPS: Medical Expenditure Panel Survey
MJFF: The Michael J. Fox Foundation for Parkinson's Research
MSA: Multiple System Atrophy
NH: Non-Hispanic
NHIS: National Health Interview Survey
NPV: Net present value
NPV: Net Present value
OOP: out-of-pocket
OP: Hospital outpatient
OTDI: Other types of disability income
PD: Parkinson's Disease
PSP: Progressive Supranuclear Palsy
PWPD/AP: Persons with Parkinson's Disease or atypical parkinsonism
ResDAC: Research Data Assistance Center
SSDI: Social security disability insurance
SSI: Supplemental security income
TEP: Technical Expert Panel

Table of Acronyms

T-MSIS: Transformed Medicaid Statistical Information System

USD: United States Dollars

VP: Vascular Parkinsonism

Glossary of Terms

Glossary Term	Glossary Definition
Absenteeism	Workdays lost because of illness or other health problems, calculated by <i>multiplying</i> the number of days' work missed in an average month X average number of months employed over past 12 months X average daily earnings among those whose current job status is part-time or full-time
Attributable costs/ Excess medical costs	Defined as the difference in per capita direct medical costs between those diagnosed with PD or AP and a comparison group with same age, gender, race/ethnicity and insurance but without PD or AP.
Atypical parkinsonism	A group of neurodegenerative disorders that share features with Parkinson's disease, but have distinct features and often more rapid disease progression; includes dementia with Lewy bodies (DLB), multiple system atrophy (MSA), progressive supranuclear palsy (PSP), corticobasal degeneration/syndrome (CBD/S), and vascular parkinsonism (VP)
Care partner	Unpaid caregivers that provide care for persons with Parkinson's disease or atypical parkinsonism
Corticobasal degeneration/syndrome	An atypical parkinsonism, also called, "corticobasal syndrome," is a neurodegenerative disorder characterized by movement and cognitive difficulties and deterioration of the cerebral cortex and basal ganglia brain structures; identified by ICD-10 diagnosis code G31.85
Dementia with Lewy bodies	An atypical parkinsonism and type of dementia characterized by cognitive and movement problems and caused by build up of Lewy body proteins in brain cells; identified by ICD-10 diagnosis code G31.83
Direct medical costs	Cost of medical care such as doctor visits, hospitalizations, and prescription drugs paid for by insurance and patients
Durable medical equipment	An equipment that is durable, used for a medical reason, typically only useful to someone who is sick or injured, used at home, and expected to last at least 3 years
Hospital inpatient	Includes acute inpatient hospital, critical access hospital
Hospital outpatient	Includes emergency department, urgent care, end-stage renal disease treatment facility, and ambulance
Incidence	The number of newly diagnosed individuals out of the population at risk (i.e., those without evidence of diagnosis for at least 24 months)
Indirect costs	Costs that are not directly linked to medical care, but are a result of disease or illness (e.g., leaving the workforce due to illness or care responsibilities)
Multiple system atrophy	A neurodegenerative disorder that affects movement and autonomic functions; identified by ICD-10 diagnosis codes G23.2 or G90.3
Non-acute institutional care	Includes post-acute and long-term care, skilled nursing facility, rehabilitation facility, hospice
Non-medical costs	Include paid daily non-medical care, home modifications, one-time accessible home purchase, motor vehicle modification, hiring someone to do household chores/provide services other than patient care, financial and legal planning, respite for care partner, and other increased transportation expenses

Glossary Term	Glossary Definition
Office visits/ambulatory care	Includes physician or clinic office visits, telehealth, physical therapy, occupational therapy, home-based care, laboratory facility, ambulatory surgery, and other unlisted facilities
Other insurance type	Includes Veterans Administration benefits or TRICARE, Indian Health Services, other health plans, and uninsured
Out-of-pocket costs	Medical expenses not covered by insurance and paid for by patients and families (e.g., over-the-counter medications, supplies, classes)
Parkinsonism	Parkinsonism is a motor syndrome defined by bradykinesia, rigidity and tremor at rest, which is a prominent feature in many neurodegenerative disorders, including Parkinson's disease. These disorders significantly impact the daily functioning and quality of life of affected individuals
Per capita	Amount per person in a given group (e.g., PD/AP or comparison group)
Presenteeism	How much work performance is hindered by health, calculated by <i>multiplying</i> the number of days' work less productive in an average month X average number of months employed over past 12 months X average daily earnings among those whose current job status is part-time or full-time X adjustment factor to reflect a partial days' worth of productivity
Prevalence	Number of persons with Parkinson's disease or atypical parkinsonism among the U.S. adult population in 2024
Prodromal symptoms	Early signs that appear before formal diagnosis.
Progressive supranuclear palsy	An atypical parkinsonism that affects movements, walking, balance, and eye movement; identified by ICD-10 code G23.1
Social productivity loss	Reduction in hours spent performing charity work, providing help to family, friends or neighbors, or participating in community or political organizations
Vascular parkinsonism	An atypical parkinsonism and movement disorder caused by blood flow issues in the brain; identified by ICD-10 code G21.4

Executive Summary

Why we did this study: Parkinson's disease (PD) and atypical parkinsonisms (AP) are progressive neurodegenerative disorders which impose a substantial socioeconomic burden on patients, families, and healthcare systems due to the long-term care, loss of productivity, and extensive costs associated with disease progression. This study seeks to understand and quantify these costs by estimating the current (2024) and future economic burden of PD and AP in the United States.

What we did: We calculated per-person estimates of (1) direct medical costs, (2) indirect costs, and (3) non-medical costs and medical expenses not covered by insurance related to a person's PD and AP care. Example direct medical costs are doctor visits, hospitalizations, and prescription drugs; indirect costs include productivity loss and earnings loss related to premature death; non-medical costs include household expenditures for therapeutic goods and activities. The direct and indirect costs specifically attributable to PD/AP were determined by comparing costs for people with PD/AP against a demographically-similar comparison group. We multiplied these per-person estimates by an estimated prevalence of PD and AP in the U.S. to calculate the total economic burden. Our calculations are based on government-provided data on healthcare utilization (e.g., Medicare and Medicaid claims, CDC, CMS survey data and U.S. Census data), private medical insurer data, and direct surveys of people living with PD/AP and their care partners.

What we found: For the 1.2 estimated million people living with PD or AP in the U.S., the total economic burden for 2024 is estimated to be \$82.2 billion. We estimate that 30% of the cost is direct medical, 32% is indirect, 22% is non-medical, 10% disability benefit costs, and 7% out-of-pocket expenses not covered by insurance. As 90% of people living with PD and AP are covered by Medicare or Medicaid, along with disability benefits costs, the cost to government programs is substantial. Based on current data, we project that, by 2045, nearly 1.7 million people will be living with PD or AP in the U.S. and the economic burden will grow to approximately \$112.4 billion. Other noteworthy findings include:

- We saw greater prevalence of PD/AP among younger age groups, suggesting increases in incidence at the population level and supported by our analysis of those newly diagnosed in claims data.
- In general, those with PD/AP under 65 years of age had higher per-capita direct medical costs than older age groups.
- Previous reports may have significantly underestimated non-medical costs. We identified new major contributors to economic burden for those with PD/AP to obtain accessible housing or hire assistance for tasks of daily living, and for additional economic burden incurred by care partners in conjunction with their caregiving activities. In addition, we estimated over \$8 billion in indirect costs for care partners alone. The per capita burden for people living with PD/AP and their care partners exceeds that for those with other conditions such as diabetes.
- While per-capita medical costs overall have increased approximately 17% from 2017, the proportion of medical costs attributable to Parkinson's has decreased slightly. That is, per-capita medical costs increased by a greater magnitude for the comparison group without PD or AP relative to those with PD/AP, thus narrowing the attributable difference in medical costs. This may be due to increased per-capita costs due to the introduction of new high-cost treatments, particularly among the general Medicare population (e.g., aducanumab, gene therapies, and GLP-1 agonists), or may be an unanticipated artifact of COVID-10 mortality rates among individuals with advanced PD/AP progression.

- We also quantified per capita excess medical costs exceeding \$10,000 in the 12 months prior to diagnosis with PD or AP.
- The overwhelming majority of direct medical costs continue to be borne by the U.S. government, with 90% of the costs related to PD and AP by individuals with PD/AP enrolled in Medicare.
- Considering excess direct medical costs paid for by Medicare and Medicaid combined with disability benefit costs, this equates to more than \$25 billion in costs related to PD and AP carried by the government with the remaining economic burden falling on PWPD/AP, their families, and employers.

Implications for readers: In 2019, we had estimated that the economic burden of PD/AP would not reach \$79 billion until 2037; now, we estimate the U.S. has recently hit that mark. Our future projections of economic burden assume that incidence holds steady – if trends toward increased incidence continue, the total cost would also grow faster than this current projection. Our estimates also do not take into consideration potential impacts of future disease-modifying treatments; an economic model for the impacts of such treatments is outside the scope of this report. This study is, to the best of our knowledge, the most comprehensive review to date of the non-medical costs incurred by households with PD/AP. However, there may still be other hidden costs of PD/AP which were not captured by our analysis. While this is the first study specifically covering the economic burden of AP, more research is recommended to further explore the cost burden on this community, given limitations of the data sources available at the time of this work.

Brief Report

Parkinsonism is a motor syndrome defined by bradykinesia, rigidity and tremor at rest, which is a prominent feature in many neurodegenerative disorders, including Parkinson's disease. These disorders significantly impact the daily functioning and quality of life of affected individuals [1]. Approximately 10-15% of individuals with parkinsonism cases are diagnosed with PD [2], with the remaining individuals diagnosed with an atypical parkinsonism (AP) [or Parkinson's related disorders], including dementia with Lewy bodies (DLB), multiple system atrophy (MSA), progressive supranuclear palsy (PSP), corticobasal degeneration/syndrome (CBD/S), or vascular parkinsonism (VP) [3].

PD and AP impose a substantial socioeconomic burden on patients, families, and healthcare systems due to the long-term care required, loss of productivity, and extensive costs associated with disease progression [4]. Previously, the Lewin Group collaborated with the Michael J. Fox Foundation for Parkinson's Research (MJFF) on a comprehensive economic burden study that estimated a prevalence of 1.04 million patients with PD/AP in the United States (U.S.) in 2017, with a total economic burden of \$51.9 billion (in 2017 USD), and by 2037, the projected prevalence is expected to exceed 1.6 million, with the economic burden rising to over \$79 billion [5].

Recent reports suggest that PD incidence and disease burden have been underestimated, putting incidence in the U.S. as much as 50% higher than previously estimated [6, 7]. PD typically progresses slowly. While AP may present similarly to PD, patients with AP may experience more rapid disease progression and may benefit less from existing PD treatments [8]. The impact of AP on direct and indirect costs is not fully understood. Additionally, there has been limited reporting on the impact on care partners and families, as well as the medical costs of the pre-diagnosis phases of PD and AP, where early intervention could potentially alter the disease course and reduce long-term costs [9]. Given these gaps, improved estimates of the tangible financial burden of PD and AP, on persons with PD or atypical parkinsonisms (PWPD/AP), families and public programs is warranted.

To support MJFF in its efforts to improve knowledge about the lived experience and economic burden of PD and AP on patients, families, and care partners, Lewin conducted a comprehensive study, building on and enhancing our prior work, to estimate the current (calendar year 2024) and future (20-year projection 2025-2045) economic burden of PD and AP in the U.S. adult population. Additionally, we estimated the costs of disease in the 12 months before a formal diagnosis. The objective of this study was to capture the economic impact of PD and AP for PWPD/AP, their unpaid care partners and families, on the healthcare system, and from a societal perspective. Specifically, we estimated the 2024 economic burden of PD and AP in terms of direct medical costs to payers and patients, indirect costs and productivity loss, non-medical costs and out-of-pocket expenses not covered by insurance and paid by PWPD/AP. We also estimated costs prior to formal diagnosis and future economic burden. We complemented our economic burden estimates with a description of the care partner experience.

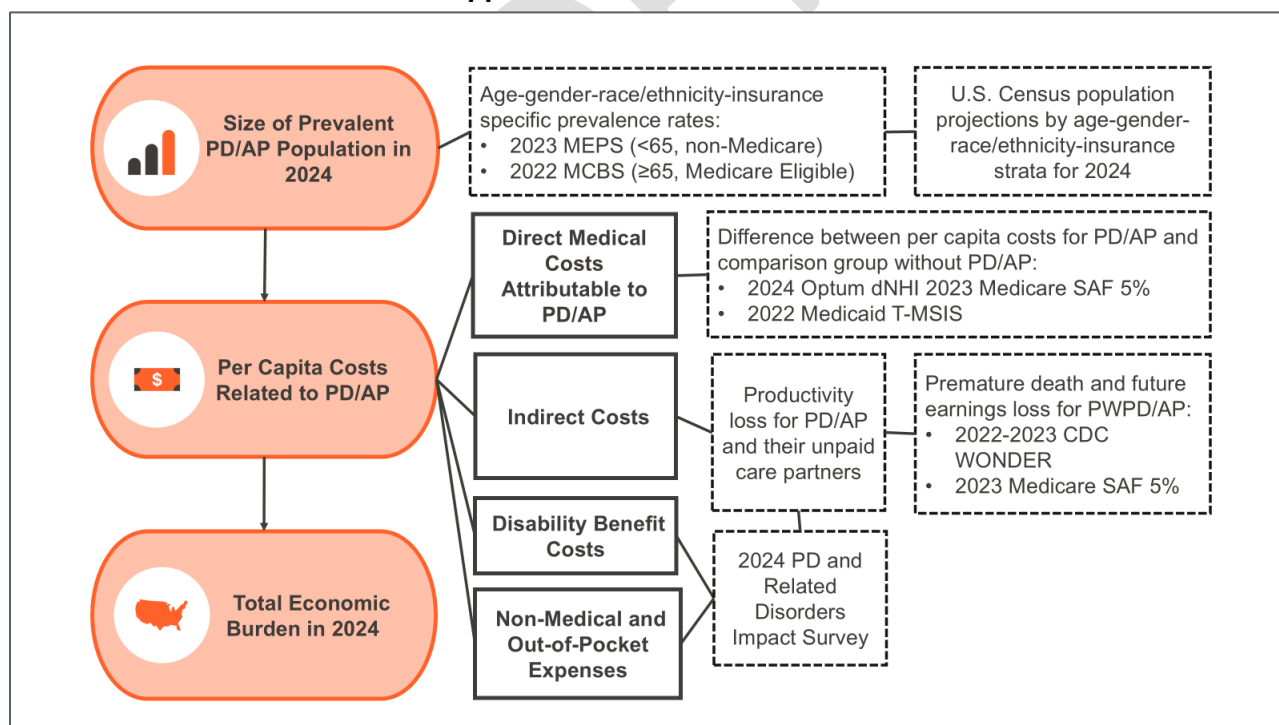
Approach

Similar to our previous report, we took a prevalence-based approach in estimating the burden of PD and AP in 2024, where the prevalence of PD and AP is combined with per-capita cost to derive national economic burden, by population characteristics. We used multiple data sources to estimate the prevalence and cost components of PD and AP. We used the Census population projections combined with the Medicare Current Beneficiary Survey (MCBS) and the Medical Expenditure Panel Survey (MEPS) to estimate the

prevalence of PD. Because neither MCBS nor MEPS allows the identification of AP diagnoses, we relied on Medicare, Medicaid, and commercial administrative claims data sources to ascertain prevalence of AP diagnoses relative to PD diagnoses using ICD-10 codes. Then, we estimated the PD and AP prevalence based on the ratio of the specific age-gender-insurance strata in the two populations from claims and the PD prevalence from MCBS and MEPS. Our previous report used ICD-9 diagnosis codes to identify PD and other neurodegenerative conditions (including PSP and CBD/S) but did not distinguish between PD and AP prevalence rates. This updated study relies on ICD-10 diagnosis codes which allow us to differentiate and include additional AP diagnoses.

To estimate the direct medical cost of PD and AP, we used the MCBS cost file, claims data from Medicare Standard Analytic File (SAF) 5% sample, the Transformed Medicaid Statistical Information System (T-MSIS), and Optum de-identified Normative Health Information data (dNHI - a large claims database of privately insured individuals covered by a large national payer). Our comparison group did not consider comorbid conditions as this was out of scope of this study. We calculated direct costs as the difference in total annual paid amount between PWP/AD and a comparison group (based on age, gender, race/ethnicity, and insurance) without PD or AP. We used CDC WONDER data and Medicare claims to estimate future earnings loss due to premature deaths attributable to PD or AP. We directly surveyed PWP/AD and their care partners to estimate indirect and non-medical costs and added questions to capture the burden on care partners and additional non-medical costs such as home modifications and transportation costs. Exhibit ES 1 illustrates the cost calculation and data sources.

Exhibit ES 1. Prevalence-Based Approach to Estimate Economic Burden



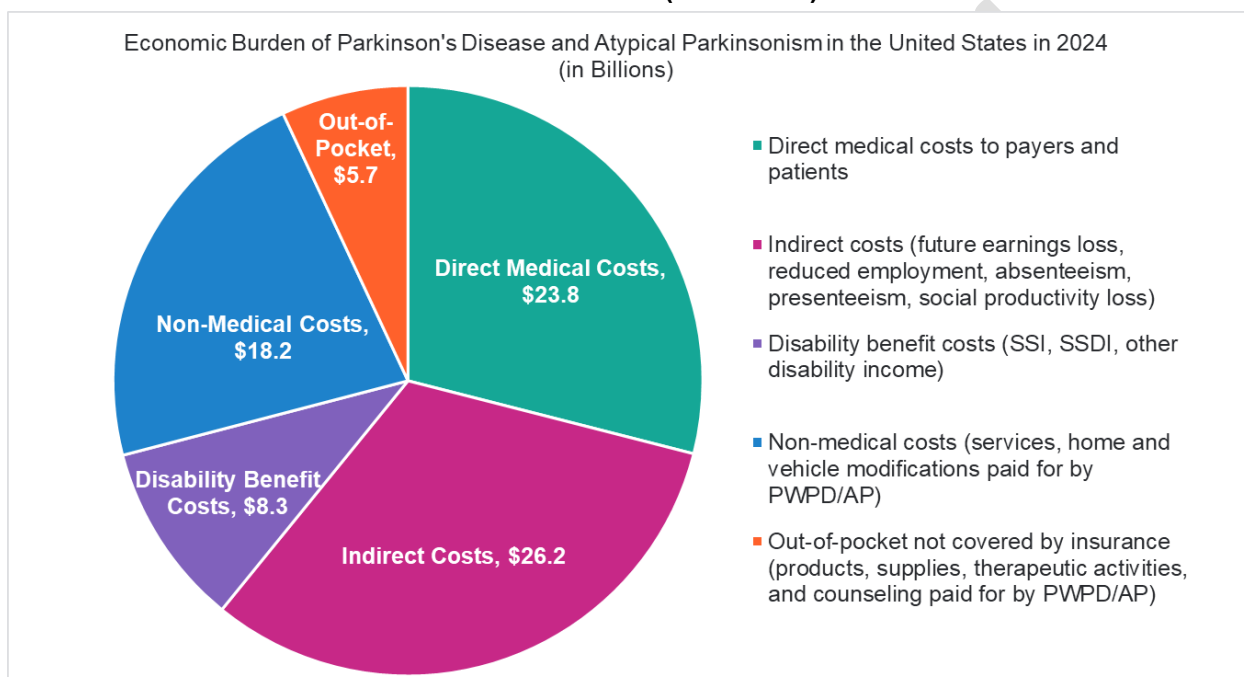
Abbreviations: PD Parkinson's Disease; AP Atypical Parkinsonism; dNHI Optum de-identified Normative Health Information; SAF Medicare Sample Analytic File; MCBS Medicare Current Beneficiary Survey; MEPS Medical Expenditure Survey; CDC Centers for Disease Control and Prevention; T-MSIS Transformed Medicaid Statistical Information System; WONDER Wide-ranging Online Data for Epidemiology Research.

Study Highlights

Total Economic Burden of Parkinson's Disease and Atypical Parkinsonism

The estimated total economic burden of PD and AP in 2024 was \$82.2 billion, including \$23.8 billion in excess direct medical costs attributable to PD and AP, \$26.2 billion in indirect costs for PWPD/AP and their unpaid care partners, \$8.3 billion in disability benefit costs, \$18.2 billion in non-medical costs and \$5.7 billion in out-of-pocket medical costs not covered by insurance and paid by PWPD/AP (Exhibit ES 2).

Exhibit ES 2. Total Economic Burden of Parkinson's Disease and Atypical Parkinsonism in the U.S. in 2024 (in Billions)



Source: Lewin analyses of PD and AP prevalence using 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2024; combined with direct medical cost estimates using 2024 Optum claims, 2023 Medicare Standard Analytical File 5% sample claims, 2022 Transformed Medicaid Statistical Information System (T-MSIS), 2022 Medicare Current Beneficiary Survey (MCBS), and other costs (indirect, non-medical, disability benefit, and out-of-pocket) from the 2024 Impact of Parkinson's and Related Disorders Survey.

*CPI adjusted to 2024 USD.

Study Findings

Prevalence

The size of the population with PD or AP by population characteristics is shown in Exhibit ES 3. An estimated 1.2 million individuals, aged 18 years and older, in the U.S. have AP or PD in 2024. The prevalence of PD and AP increases with age, with the 65 and older persons representing the largest share (75%) of the PD and AP population. Males have a slightly higher prevalence than females, 0.57% and 0.35% respectively. Overall, the prevalence rate of PD or AP in non-Hispanic whites is 1.3 times the prevalence of the non-Hispanic black and Hispanic populations and more than four times that of the non-Hispanic other population, with more than 910,000 in the White subgroup (75% of total PD or AP population). The vast majority (87%) of the PD or AP population are eligible for Medicare coverage. Within the Medicare eligible population, the prevalence rate for non-Hispanic Black is higher than for Hispanic

(data not shown). It is worth noting that the PD prevalence rate for those 50-64 years old in this study is higher than that estimated in the previous report (0.39% vs. 0.29%) [5].

Exhibit ES 3. Parkinson's Disease and Atypical Parkinsonism Prevalence by Population Characteristics in 2024

	No. of Persons Estimated to Have PD or AP	U.S. Population	Prevalence Rate
Age group, years			
18-49	56,816	141,792,556	0.04%
50-64	240,838	61,660,017	0.39%
65-74	376,698	35,223,309	1.07%
≥75	539,611	26,298,663	2.05%
Gender			
Male	744,131	130,227,394	0.57%
Female	469,832	134,747,151	0.35%
Race/Ethnicity			
NH White	914,204	161,154,757	0.57%
NH Black	138,181	31,955,514	0.43%
Other	62,358	24,560,303	0.25%
Hispanic	99,363	47,303,971	0.21%
Insurance			
Private	105,803	138,862,094	0.08%
Medicare	1,056,543	73,280,221	1.44%
Medicaid	25,427	28,432,466	0.09%
Other Insurance*	26,190	24,399,765	0.11%
Overall	1,213,963	264,974,545	0.46%

Source: Lewin analyses of 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2024.

*Other insurance includes other insurance not listed above such as Indian Health Services, military, and uninsured.

Direct Medical Costs

The direct medical cost of Parkinson's and atypical parkinsonism by age, gender, race/ethnicity, and insurance coverage are shown in Exhibit ES 4. Overall, the excess direct medical cost per capita in 2024 was \$19,644. Per capita excess direct medical costs attributable to PD and AP were higher for those under 50 years of age (\$24,934) compared with older age groups (approximately \$19,000). Per capita costs were also higher for non-Hispanic black compared with other race/ethnicities. Total excess medical cost attributable to PD or AP was higher for Medicare beneficiaries compared with other insurance types. Furthermore, we observed higher average per capita costs among Medicare beneficiaries 18-65 compared with those 65 years and older (\$49,655 compared with \$39,007, respectively, data not shown).

The Medicare eligible population accounted for almost 90% of \$23.8 billion in total excess medical costs attributable to PD and AP in 2024; individuals are generally eligible for Medicare if they are either at least 65 years old or have been receiving federal disability benefits for at least 24 months [10]. The population 65 years of age and older accounts for an estimated 75% of the total excess medical costs, the overwhelming majority of whom are insured by Medicare. More than 75% of Medicare beneficiaries under 65 years of age have one or more disability, compared with 32% of those 65-74 and 44% of those 75-84 [11]. The non-

Hispanic white group represents 67% of the total medical costs. Non-acute institutional care and hospital inpatient care were the highest excess medical cost categories.

Exhibit ES 4. Total (in Billions) and Per Capita Direct Medical Cost Attributable to Parkinson's Disease and Atypical Parkinsonism by Age, Gender, and Insurance Coverage in 2024

	Total Excess Medical Cost* Attributable to PD or AP (in Billion \$)	Percentage of the Total	Per Capita Excess Medical Cost (\$)
Age			
18-49	\$1.42	6%	\$24,934
50-64	\$4.87	20%	\$20,239
65-74	\$7.27	30%	\$19,290
≥75	\$10.27	43%	\$19,030
Gender			
Male	\$14.47	61%	\$19,448
Female	\$9.35	39%	\$19,910
Race/Ethnicity			
NH White	\$15.89	67%	\$17,379
NH Black	\$4.18	18%	\$30,234
Other	\$1.29	5%	\$20,612
Hispanic	\$2.48	10%	\$24,917
Insurance			
Private	\$1.39	6%	\$13,181
Medicare	\$21.25	89%	\$20,117
Medicaid	\$0.99	4%	\$38,942
Other insurance^	\$0.19	1%	\$7,150
Type of service			
Non-Acute Institutional Care	\$10.04	42%	\$8,267
Hospital Inpatient	\$6.13	26%	\$5,053
Hospital Outpatient	\$1.83	8%	\$1,507
Physician Office/ambulatory care	\$4.08	17%	\$3,363
Durable Medical Equipment	\$0.30	1%	\$244
Prescription Medication	\$1.47	6%	\$1,210
Overall	\$23.85		\$19,644

Source: Lewin analyses of PD and AP prevalence using 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2024; combined with direct medical cost estimates using 2024 Optum claims, 2023 Medicare Standard Analytical File 5% sample claims, 2022 Transformed Medicaid Statistical Information System (T-MSIS), and 2022 Medicare Current Beneficiary Survey (MCBS).

*CPI adjusted to 2024 USD.

^Other insurance includes other insurance not listed above such as Indian Health Services, military, and uninsured.

Indirect and Non-Medical Costs

In addition to direct medical costs, we estimated total indirect and non-medical costs of PD and AP was \$58.4 billion in 2024 (Exhibit ES 5). The \$26.2 billion in indirect costs comprised of \$17.9 billion for PWP/AD/AP and an additional \$8.3 billion for their unpaid care partners in earnings loss, reduced employment, and labor market productivity losses (absenteeism and presenteeism) were the largest categories. The remaining \$23.9 billion in non-medical costs and medical-related out-of-pocket expenses

not covered by insurance incurred to treat and manage PD and AP, the largest contributors were motor vehicle modifications, paid non-medical household help and counseling for PWPDP/AP and care partners. We also include an estimated \$8.3 billion in disability benefit costs for PWPDP/AP. Per capita indirect costs for PWPDP/AP and care partner were \$48,101, which is greater than per capita indirect costs for other conditions such as diabetes (per capita indirect cost for diabetes was estimated to be around \$4,500 in 2022 USD) [12].

Exhibit ES 5. The Total (in Billions) and Per Capita Indirect and Non-Medical Cost of Parkinson's Disease and Atypical Parkinsonism by Cost Component in 2024

	Total Indirect and Medical Costs (in Billion \$)^			Per Capita (\$)		
	PWPDP/AP Loss	Care Partner Loss	PWPDP/AP & Care Partner	PWPDP/AP Loss	Care Partner Loss	PWPDP/AP & Care Partner
Indirect Costs						
Premature death	\$3.12	NA	\$3.12	\$2,572	NA	\$2,572
Reduced employment	\$6.75	\$1.72	\$8.46	\$5,557	\$1,413	\$6,970
Absenteeism	\$3.77	\$3.84	\$7.61	\$3,108	\$3,165	\$6,273
Presenteeism	\$3.26	\$2.39	\$5.65	\$2,682	\$1,972	\$4,653
Social productivity loss in volunteer work	\$1.07	\$0.30	\$1.38	\$883	\$251	\$1,134
Disability Benefit Costs						
Supplemental Security Income (SSI)	\$1.00	NA	\$1.00	\$827	NA	\$827
Social Security Disability Insurance (SSDI)	\$2.56	NA	\$2.56	\$2,107	NA	\$2,107
Other disability income	\$4.71	NA	\$4.71	\$3,882	NA	\$3,882
Non-Medical Costs						
Motor vehicle modification	\$7.77	NA	\$7.77	\$6,399	NA	\$6,399
Hiring someone to do household chores/provide services other than patient care	\$4.02	NA	\$4.02	\$3,313	NA	\$3,313
Home modifications	\$2.34	NA	\$2.34	\$1,926	NA	\$1,926
Paid daily non-medical care	\$2.13	NA	\$2.12	\$1,756	NA	\$1,756
Financial and legal planning	\$0.80	NA	\$0.80	\$658	NA	\$658
One-time accessible home purchase expenses	\$0.74	NA	\$0.74	\$605	NA	\$605
Respite for care partner	\$0.19	NA	\$0.19	\$157	NA	\$157
Other increased transportation expenses	\$0.18	NA	\$0.18	\$151	NA	\$151
Out-of-pocket expenses (not covered by insurance)						
Counseling (patient education, psychotherapy, nutrition counseling, dietician) for PWPDP/AP and care partners)	\$4.22	NA	\$4.22	\$3,478	NA	\$3,478

	Total Indirect and Medical Costs (in Billion \$)^			Per Capita (\$)		
	PWPD/AP Loss	Care Partner Loss	PWPD/AP & Care Partner	PWPD/AP Loss	Care Partner Loss	PWPD/AP & Care Partner
Products (over-the-counter and supplements)	\$1.12	NA	\$1.12	\$922	NA	\$922
Supplies (e.g., adaptive clothing, feeding equipment)	\$0.22	NA	\$0.22	\$179	NA	\$179
Therapeutic Activities (e.g., gym, exercise classes, online classes, home exercise equipment)	\$0.17	NA	\$0.17	\$139	NA	\$139
Overall	\$50.14	\$8.26	\$58.39	\$41,301	\$6,800	\$48,101

Source: Lewin analyses 2024 PD and Related Disorders Impact Survey data, supplemented with other data sources such as CDC WONDER multiple cause of death files, Bureau of Labor Statistics earnings data; combined with prevalence estimated using 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2024.

PWPD/AP is Person with Parkinson's disease/Parkinson's Related Disorders.

*Costs in 2024 USD as survey respondents were asked to report their expenses in the past 12 months, which included 2024.

^May not sum to Overall row due to rounding.

Incidence and Costs Prior to Formal Diagnosis

In order to estimate the medical costs prior to diagnosis with PD and AP, we estimated incidence in three large administrative claims data sources. Incidence rates per 100,000 population in person years are substantially higher for those 65 years and older (234 per 100,000) compared with those under 65 (22 per 100,000, Exhibit ES 6). Incidence rates were higher in males compared with females under 65 (27 and 17 per 100,000, respectively) and 65 years and overs (302 and 181 per 100,000, respectively).

Exhibit ES 6. Incidence* of PD and AP per 100,000 by Age, Gender and Insurance

	Incident Cases	Person years	Incidence per 100,000 Person years
18 to 64	3,570	16,570,172	21.5
Gender			
Male	2,078	7,840,138	26.5
Female	1,492	8,730,034	17.1
Insurance			
Private	961	5,573,604	17.2
Medicare	196	270,844	72.4
Medicaid	2,040	9,473,651	21.5
≥65	5,447	2,324,090	234.4
Gender			
Male	3,095	1,026,228	301.6
Female	2,352	1,297,862	181.2
Insurance			
Medicare	5,447	2,324,090	234.4

Source: Lewin analysis of Optum administrative claims data 2021-2024, Medicare SAF 5% 2022-2023, and Transformed Medicaid Statistical Information System (T-MSIS) 2021-2022.

*Incidence ascertained by 24 months clean lookback without prior diagnosis of PD or AP.

We estimated the annual per capita medical costs in the 12 months prior to formal diagnosis and compared with the average costs for the same age and insurance type with no PD or AP diagnosis. Relative to costs for the same age group and insurance type without diagnosis, costs were higher overall for PWP/AD/AP in the 12 months prior to formal diagnosis (Exhibit ES 7).

Exhibit ES 7. Per Capita Medical Costs Prior to Formal diagnosis with PD or AP by Age Group and Insurance

Type of Service	<65			≥65
	Private	Medicare	Medicaid	Medicare
Type of Service				
Non-acute institutional	\$128	\$10,444	\$5,290	\$8,163
Hospital inpatient	\$4,681	\$11,368	\$2,068	\$7,971
Hospital outpatient	\$5,469	\$5,160	\$501	\$4,277
Office visits/ambulatory care	\$3,722	\$8,056	\$10,725	\$7,425
Durable medical equipment	\$32	\$667	\$121	\$461
Prescription medications	\$2,116	\$3,668	\$2,204	\$2,535
Total	\$16,147	\$39,363	\$20,910	\$30,832

Lewin analysis of Optum dNHI administrative claims 2024, Medicare SAF 5% 2023, and Transformed Medicaid Statistical Information System (T-MSIS) 2022.

*CPI adjusted to 2024 USD.

Costs among privately insured aged 18-64 were 30% higher. Among Medicare beneficiaries ages 18-64 and 65 years and older, costs were 60% and 50% higher for PWP/AD/AP prior to diagnosis compared with those the same age without PD or AP diagnosis (Exhibit ES 8). Among Medicaid beneficiaries, costs were more than 5-fold greater for PWP/AD/AP prior to diagnosis compared with those the same age without PD or AP diagnosis.

Exhibit ES 8. Per Capita Medical Costs Prior to Formal Diagnosis Relative to Comparison Group by Age Group and Insurance

	<65			≥65
	Private	Medicare	Medicaid	Medicare
Prior to diagnosis with PD/AP	\$16,147	\$39,363	\$20,910	\$30,832
Comparison group without PD/AP	\$12,482	\$24,392	\$3,702	\$20,326
Excess	\$3,665	\$14,987	\$17,208	\$10,506
Cost Ratio[^]	1.3	1.6	5.6	1.5

Lewin analysis of Optum dNHI administrative claims 2022-2024, Medicare SAF 5% 2022-2023, and Transformed Medicaid Statistical Information System (T-MSIS) 2022.

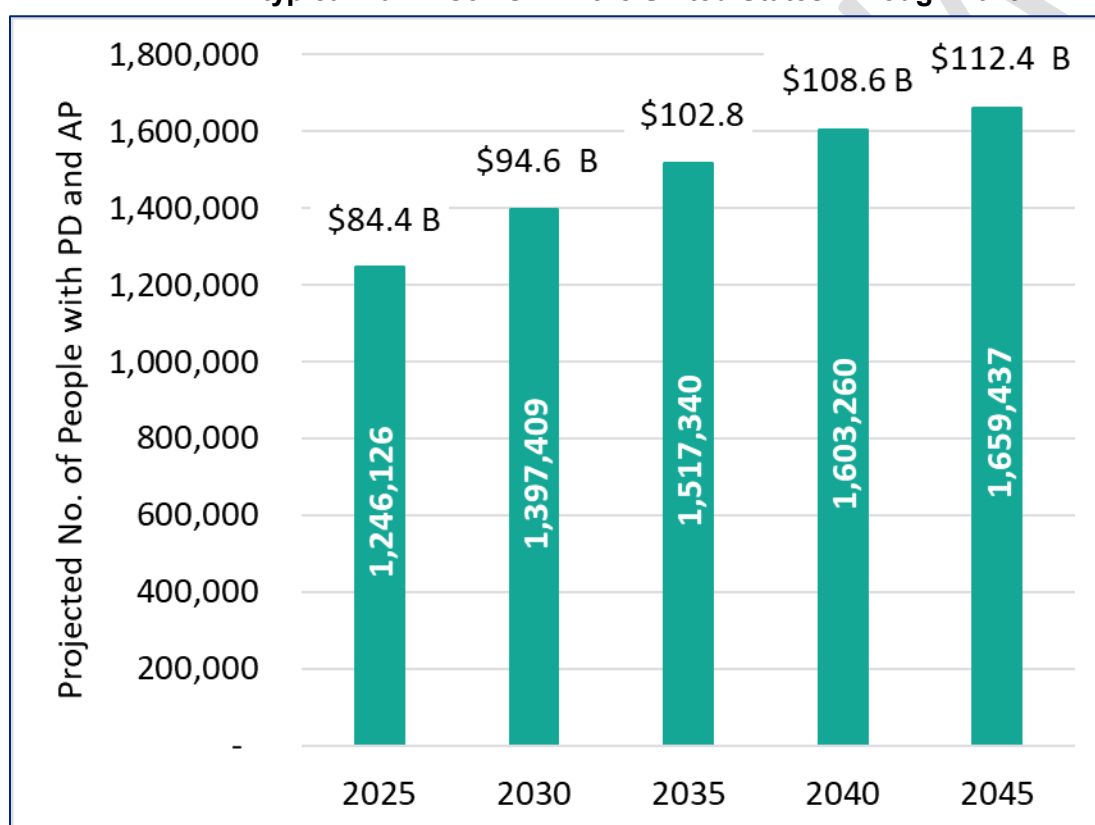
*CPI adjusted to 2024 USD.

^Cost ratio for average per capita medical costs prior to diagnosis relative to same age group and insurance type with prevalent PD and AP.

Projected Future Costs

We estimated the size of the future PD and AP population in the U.S. and the estimated total economic burden in current dollars (Exhibit ES 9). Assuming fixed prevalence rates and accounting for population growth based on U.S. Census projections by age and gender, we projected the PD and AP prevalence to increase from approximately 1.2 million PWP/DP/AP in 2025 to 1.5 million in 2035 and then to approximately 1.7 million in 2045. The corresponding total economic burden is projected to be \$84.4 billion in 2025 and then \$102.8 billion and \$112.4 billion in 2035 and 2045, respectively.

Exhibit ES 9. Projected Prevalence and Economic Burden of Parkinson's Disease and Atypical Parkinsonism in the United States Through 2045



Source: Prevalence - Lewin analyses of 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projections for 2025-2045. Economic burden - Lewin analysis of PD and AP prevalence and economic burden in 2024 combined with Census population projections.

Discussion

This study updates previous estimates of prevalence and economic burden of Parkinson's disease and related disorders in the United States. The total economic burden of PD and AP in 2024 was \$82.2 billion, including \$23.8 billion in excess direct medical costs attributable to PD and AP and an additional \$26.2 billion in indirect costs for PWP/DP/AP and their unpaid care partners, \$8.3 billion in disability benefit costs, \$18.2 billion in non-medical costs and \$5.7 billion in out-of-pocket medical costs not covered by insurance and paid by PWP/DP/AP. This study expands on previous economic burden estimates by including a broader

range of atypical parkinsonism diagnoses and examining medical costs prior to formal diagnosis with PD or AP.

Another highlight of this study is the newly enhanced 2024 PD and Related Disorders Impact Survey. This survey included questions to collect information from PWP/DP/AP and their care partners on symptoms, workforce participation and productivity loss, and an array of non-medical costs included in the previous Social and Financial Impact of Parkinson's Disease Survey. In order to more fully capture how people living with PD and AP and their unpaid care partners are impacted by disease, we added new questions to capture more detail on non-medical costs, such as legal and financial planning, medical-related expenses not covered by insurance, as well as care partner experience and well-being.

Previous studies reported different estimates and projections of the national prevalence and costs of PD and related disorders, driven by the source of the data, age of population studied, region, year of the study, and method of analysis (Exhibit ES 10). We estimated the size of the population with PD and AP in 2024 to be 1.21 million in 2024; using consistent methodology and more recent data, this reflects an increase in the size of the PD/AP population of approximately 17% since our previous report. Our study relied on nationally representative data sources to estimate the size of the population with PD and AP so that our estimate includes multiple insurance types. Other studies relied on Medicare claims data to estimate prevalence, which may underestimate the size of the population by not including other insurance types [13, 14, 15]. For instance, a recent study by Pearson et al reported approximately 685,000 Medicare beneficiaries with PD in 2019 [13].

Exhibit ES 10. Comparison of the Current Study with PD Burden Estimates in the Literature

U.S. PD Burden Study	Estimated Size of Prevalent Population and Year	Direct Cost	Indirect & Non-Medical Costs
Current study	1,213,963* in 2024	\$23.8 billion 2024 USD	\$58.4 billion 2024 USD
Pearson et al, 2023 [13]	685,000 in 2019^	<i>Did not estimate economic burden</i>	
Yang et al, 2020 [5]	1,037,211* in 2017	\$25.4 billion 2017 USD	\$26.5 billion 2017 USD
Marras et al, 2018 [14]	680,000† in 2010^†	<i>Did not estimate economic burden</i>	
Kowal et al, 2010 [16]	630,000 in 2010	\$14 billion 2018 USD	\$6.4 billion 2010 USD
O'Brien et al, 2009 [17]	500,000 in 2007	\$6.2 billion 2007 USD	\$4.6 billion 2007 USD
Willis et al, 2010 [15]	450,000 in 2005^	<i>Did not estimate economic burden</i>	
Huse et al, 2006 [18]	645,000 in 2002	\$6.7 billion 2002 USD	\$16.3 billion 2002 USD

*Inclusive of Parkinson's disease and atypical parkinsonism diagnoses.

^Relied on Medicare claims data to estimate prevalence.

†Prevalence for age ≥45.

Our previous report used ICD-9 diagnosis codes to identify PD and other neurodegenerative conditions (including PSP and CBD/S) but did not distinguish between PD and AP prevalence rates. This updated study relies on ICD-10 diagnosis codes which allow us to differentiate and include additional AP diagnoses.

Our estimated prevalence of AP (DLB, MSA, PSP, CBS, Vascular parkinsonism, and Parkinsonism not otherwise specified) is 46 per 100,000 (an estimated 121,547 AP patients in 2024). Our estimates indicate a higher prevalence of individual AP conditions compared to previously reported rates. For example, compared to previously reported PSP prevalence of 2.95 per 100,000 in 2016, we estimated 4.72 per 100,000 PSP prevalence in 2024 [19].

PD/AP was associated with an excess direct medical cost of \$23.8 billion in 2024, slightly lower than our previous report [5]. Reasons for this are not entirely clear, but may reflect a combination of factors related to the broader health policy and payer landscape in recent years that may have resulted in greater increases in the general population reflected in our comparison group without PD or AP medical costs relative to increases in the PD/AP group, thus reducing the attributable difference. While per-capita medical costs overall have increased approximately 17% from 2017, the proportion of medical costs attributable to Parkinson's has decreased slightly. That is, per-capita medical costs increased by a greater magnitude for the comparison group without PD or AP relative to those with PD/AP, thus narrowing the attributable difference in medical costs. For instance, for Medicare beneficiaries where per capita costs for those with PD increased from \$37,804 in 2017 to \$40,422 in 2024 compared with \$12,993 in 2017 and \$20,294 in 2024 for the comparison group without PD or AP; this has a profound impact on the calculation of costs attributable to PD and AP as most of the medical cost of PD or AP is borne by populations eligible for Medicare coverage (89%). The difference in costs could be related to diseases with higher expenses than PD in the comparison group. For example, the comparison group in our Medicare analysis included patients with cancer and genetic diseases. In addition, new, expensive treatments such as aducanumab [for Alzheimer's disease] and the glucagon-like peptide-1 (GLP-1) agonists [newer diabetes and obesity therapy peaked in 2022-2023] were available during the current study period, but not the previous one. Another reason could be related to increased PD prevalence among the younger age group (<65), which is in line with the occurrence of young-onset Parkinson's disease [20]. This younger group is likely healthier than the older group and therefore incurred lower average per capita costs.

We estimated the total excess cost due to PD or AP in non-acute institutional care to be \$10.0 billion. Consistent with our previous study, the total costs for non-acute institutional care were the highest compared to other service types, driving the direct medical costs among the Medicare beneficiaries with PD and indicating the high demand for long-term care among older patients with PD. A recent report by the National Alliance for Caregiving found that 9% of patients with PD live in a nursing or long-term care facility [21].

To assess indirect costs, we estimated premature death, present value of future earnings, labor market employment/related earnings loss, labor market productivity loss, and social productivity. Of the \$26.23 billion indirect costs attributable to PD and AP, labor market productivity losses (absenteeism and presenteeism) were the largest categories, including \$17.9 billion PWP/AD/AP and an additional \$8.3 billion for their unpaid care partners. Of the \$23.9 billion in non-medical and out-of-pocket expenses, the largest contributors were motor vehicle modifications, paid household help and counseling for PWP/AD/AP and care partners. It is worth noting here that our current lower estimate of premature deaths due to PD/AP (18,069 in the current study compared to 23,393 in the previous study) could be related to the high mortality of PWP/AD/AP during the COVID-19 pandemic that resulted in lower premature deaths during the study period.

Incidence rates were substantially higher for those 65 years and older (234 per 100,000) compared with those under 65 (22 per 100,000). Incidence was higher among males compared with females under age 65

(27 per 100,000 and 17 per 100,000, respectively) and 65 years and older (302 per 100,000 and 181 per 100,000, respectively). In the 12 months prior to diagnosis of PD or AP, the most commonly known prodromal symptom observed by diagnosis code on a medical claim was gait disorder regardless of age or insurance. Among those ages 18 to 64, the next most common were those diagnoses related to mood or affect (major depressive disorder, mood disorder, and anxiety) and among those ages 65 and older the next most common diagnoses of the options we reviewed were major depressive disorder, anxiety, and constipation.

We estimated the annual per capita medical costs in the 12 months prior to diagnosis and compared it with the average costs for the same age and insurance type with no PD or AP diagnosis. Relative to costs for the same age and insurance type with no diagnosis, per capita costs were, on average, approximately \$10,000 higher for PWPD/AP prior to formal diagnosis.

We estimated the size of the future PD and AP population in the U.S. and the estimated total economic burden in current dollars. The PD and AP prevalence is projected to increase from approximately 1.2 million PWPD/AP in 2025 to 1.5 million in 2035 and then to approximately 1.7 million in 2045. The corresponding total economic burden is projected to be \$84.4 billion in 2025, \$102.8 billion in 2035, and \$112.4 billion in 2045.

Conclusion

By including AP diagnoses, this study provides a comprehensive picture of the 2024 economic burden of PD and AP in the U. S. While excess direct medical costs attributable to PD and related neurodegenerative conditions have remained relatively stable since 2019 due primarily to increases in costs in the comparison group, our comprehensive approach identified significantly higher indirect medical costs and non-medical costs. Our analysis of indirect medical costs underscores the increasing load borne by PWPD/AP and their unpaid care partners in terms of workforce participation, earnings loss, and productivity loss. Further, we captured previously unreported categories of non-medical costs borne by households managing PD and AP, such as motor vehicle modifications and paid household help. These indirect medical and non-medical costs, in combination with the direct medical costs attributable to PD and AP represent an area ripe for interventions to alleviate symptoms and delay disease progression that forces PWPD/AP and their care partners to leave the workforce. Our examination of prodromal features and costs in the 12 months prior to formal diagnosis with PD or AP highlight the symptom burden for PWPD/AP. Future research should investigate the patient journey, as in clinical practice PWPD/AP may experience new or additional diagnoses.

Full Study Report with Detailed Methodology

I. Background and Rationale

Parkinsonism is defined as a collection of movement disorders, including Parkinson's disease (PD), characterized by the presence of clinical motor features such as rigidity, bradykinesia, and tremor, which significantly impact the daily functioning and quality of life among affected individuals [1]. Approximately 10-15% of parkinsonism cases are PD [2] with the remaining cases manifesting as atypical parkinsonism (AP) [or Parkinson's related disorders], including dementia with Lewy bodies (DLB), multiple system atrophy (MSA), progressive supranuclear palsy (PSP), and corticobasal degeneration/syndrome (CBD/S) and vascular parkinsonism (VP) [3].

PD and AP impose a substantial socioeconomic burden on patients, families, and healthcare systems due to the long-term care required, loss of productivity, and extensive costs associated with disease progression [4]. Previously, the Lewin Group collaborated with the Michael J. Fox Foundation for Parkinson's Research (MJFF) and the Parkinson's Foundation on a comprehensive economic burden study that estimated a prevalence of 1.04 million patients with PD in the United States (U.S.) in 2017, with a total economic burden of \$51.9 billion (in 2017 USD), and by 2037, the projected prevalence is expected to exceed 1.6 million, with the economic burden rising to over \$79 billion [5].

There is some evidence to suggest that PD incidence and disease burden have been underestimated, putting incidence in the U.S. as much as 50% higher than previously estimated [[6, 7]. Limitations in earlier studies such as reliance on older epidemiological data, incomplete diagnosis capture of AP, changes over time in diagnostic coding for PD and AP, and underreporting of early-stage disease may have led to these underestimations. PD typically progresses slowly. While AP may present similarly to PD, patients with AP may experience more rapid disease progression and may benefit less from existing PD treatments. The impact of AP on direct and indirect costs, and care partner burden, is not fully understood. Additionally, there has been limited reporting on the impact on care partners and families, as well as the medical costs of the pre-diagnosis phases of PD and AP, where early intervention could potentially alter the disease course and reduce long-term costs [9]. Given these gaps, improved estimates of the tangible financial burden of PD, inclusive of AP, on Persons with PD or atypical parkinsonism (PWPD/AP), families and public programs is warranted.

To support MJFF in its efforts to improve knowledge about the lived experience and economic burden of PD and AP on patients, families, and care partners, Lewin conducted a comprehensive study, building on and enhancing our prior work, to estimate the current (calendar year 2024) and future (20-year projection through 2045) economic burden of PD and AP in the U.S. population (age 18+). Additionally, we estimated the costs of disease prior to a formal diagnosis. The burden estimates included not only the direct medical costs related to treatment and care, but also the broader economic impacts, such as work and social productivity, caregiving costs, and other financial burdens that are associated with PD and AP. The overarching objective of this study was to capture the economic impact of PD and AP for patients, care partners and families, on the healthcare system, and from a societal perspective. We complemented our economic burden estimates with a description of the care partner experience. The specific aims of this project were to:

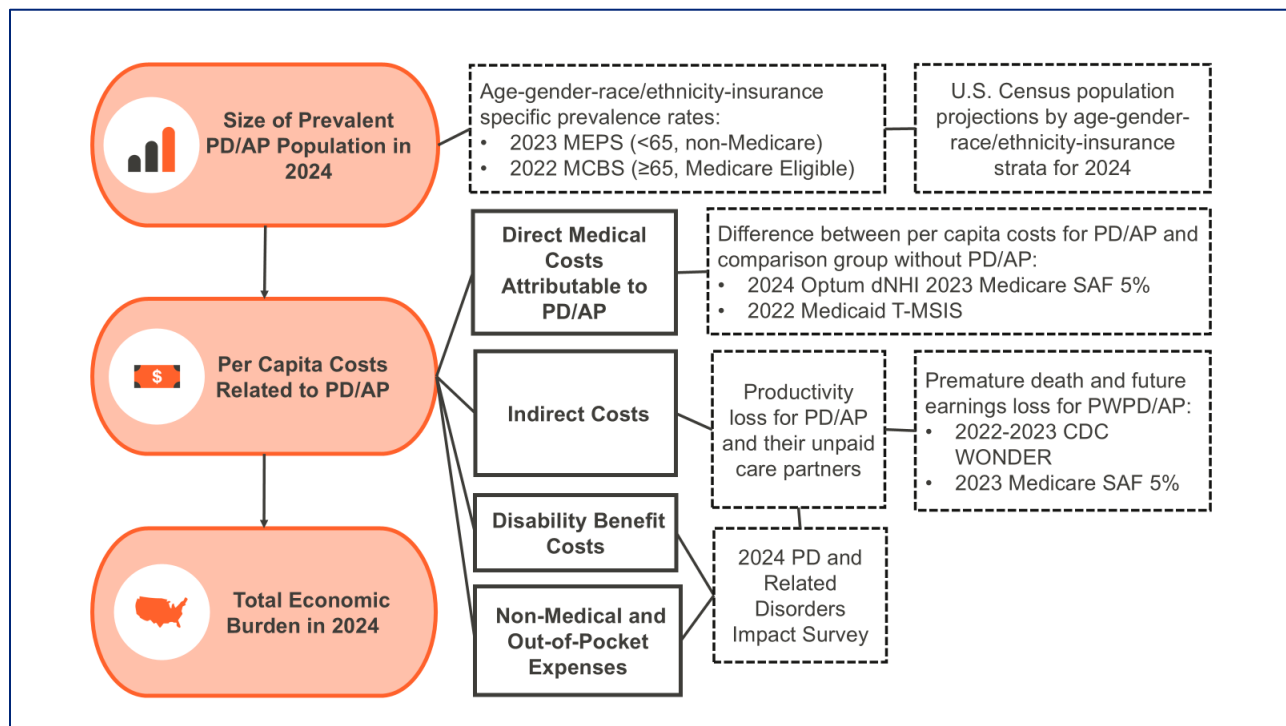
- 1) Estimate the current economic burden of PD and AP in terms of:
 - Direct medical costs for payers and patients attributable to PD/AP;

- Indirect costs, including future earnings loss, reduced employment, and productivity loss for people living with PD/AP and their unpaid care partners;
 - Disability benefit costs;
 - Non-medical and medical-related expenses not covered by insurance and paid for by PWPD/AP;
- 2) Estimate direct medical costs prior to formal diagnosis with PD or AP;
 - 3) Estimate future economic burden; and
 - 4) Describe the care partner experience.

II. Methods

We took a prevalence-based approach in estimating the burden of PD and AP in 2024 where the prevalence of PD and AP is combined with per-capita cost to derive national economic burden, by population characteristics. Due to a lack of a uniform data source and approach to estimate the total burden of PD and AP, we used multiple data sources to estimate the cost components of PD and AP. We used the U.S. Census Bureau 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, Transformed Medicaid Statistical Information System (T-MSIS), 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 PWPD/AP and those without PD or AP. Future earnings loss due to premature deaths attributable to PD was estimated using CDC WONDER data and the Medicare administrative claims, among others. We also enhanced the PD Impact Survey from the previous study to collect detailed information on indirect and non-medical costs, including reduced employment and productivity loss for PWPD/AP and their unpaid care partners, costs for the government to provide supplement disability income such as Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI), non-medical cost of PD and AP such as the cost of hiring professional non-medical caregivers to assist with daily living, home modification costs and increased transportation costs, and medical-related expenses not covered by insurance and paid for by PWPD/AP.

The disease attributable cost approach was used to estimate the direct cost of PD and AP, and a human capital approach was used to calculate the indirect costs. To obtain clinical guidance and ensure study validity, a Technical Expert Panel (TEP) was formed in collaboration with the Michael J. Fox Foundation to shepherd the study from beginning to completion. The TEP 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 2024 PD and Related Disorders Impact Survey instrument. Exhibit 1 illustrates the cost calculation steps and data sources for key cost components.

Exhibit 1. Prevalence-Based Approach to Estimate Economic Burden

Abbreviations: PD Parkinson's Disease; AP Atypical Parkinsonism; dNHI de-identified Normative Health Information; SAF Sample Analytic File; MCBS Medicare Current Beneficiary Survey; MEPS Medical Expenditure Survey; CDC Centers for Disease Control and Prevention; T-MSIS Transformed Medicaid Statistical Information System; WONDER Wide-ranging Online Data for Epidemiology Research.

A. Data Sources

There is no single data source that is sufficient to answer all the research questions of this new study. To estimate the economic burden of PD and AP, we conducted analyses of several secondary data sources to estimate disease prevalence, direct medical costs, and indirect costs related to premature death attributable to disease. In addition, we used the 2024 PD and Related Disorders Impact Survey to capture additional details on indirect costs, non-medical costs, and care partner burden.

A.1. Secondary Data Sources

A brief overview of the data sources, including their respective strengths and limitations, is presented in Exhibit 2 and described in detail below.

Exhibit 2. Overview of Secondary Data Sources

Data source	Description	Strengths	Limitations
Optum de-identified Healthcare Information (dNHI) claims data	De-identified claims, data from commercial payers and Medicare Advantage (MA) plans	Medical and pharmacy claims, membership, and ancillary data for large national sample	Lacks clinical and biomarker data, insured population only
Medicare Current Beneficiary Survey (MCBS)	Linked Medicare claims and survey-reported events	Representative national sample of 16,000 Medicare beneficiaries with detailed health and socioeconomic	Limited to Medicare population, self-reported data can be subject to recall bias

Data source	Description	Strengths	Limitations
		information; includes prescription medication costs	
Medical Expenditure Panel Survey (MEPS)	Large-scale surveys of families and individuals, their medical providers, and employers	Comprehensive cost and utilization data with patient demographics on a nationally representative sample	Limited sample size, self-reported data may introduce bias; limited granularity with 3-digit diagnosis codes
Medicare Standard Analytical File (SAF) 5% sample claims	A random 5% sample of medical claims data of traditional fee-for-service (FFS) Medicare beneficiaries	Large, nationally representative sample with linkable IDs over time and cost information	No Part D prescription claims
Medicaid T-MSIS claims data	Claims data for Medicaid beneficiaries	Includes low-income individuals, covering various services such as hospital care, doctor visits, and long-term care; includes date of death	State-level variation in coverage and reimbursement rates, missing or incomplete data in some areas
CDC Wide-ranging Online Data for Epidemiologic Research (WONDER)	Public health database with mortality and health statistics	Nationally representative, covering date and cause of death	Limited in clinical details and lacks direct link to economic data

The primary sources of information for prevalence of PD were MCBS and MEPS.

- **MCBS:** For information on Medicare beneficiaries, we used data from the MCBS (2022). 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. These data are suitable for estimating healthcare use and expenditures, as it links Medicare claims to survey-reported events and provides complete expenditures and source of payment data on all healthcare services (including those not covered by Medicare, such as skilled nursing facility services). MCBS includes comprehensive information on health services, however, it does not capture information on AP diagnoses.
- **MEPS:** For populations with other types of insurance coverage, such as TRICARE or VA, as well as the uninsured, we used the MEPS data (2023). Although the MEPS annual consolidated household survey has several 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-10 diagnosis code included in the publicly available MEPS only contains 3-digits and allows for identification of PD, but not AP.

We also conducted analyses in three administrative claims data sources to compliment these estimates of PD prevalence and to estimate prevalence of AP. These data sources included:

- **Optum de-Identified Normative Health Information (dNHI) database:** A key database that Lewin leveraged was the 2024 Optum dNHI database, a proprietary, longitudinal database comprised of statistically de-identified individual-level data. The database includes medical and pharmacy claims, enrollment information, provider, and ancillary information for approximately 160 million lives covered by commercial private insurance plans. It is geographically diverse and nationally representative by key demographic characteristics.
- **Medicare Standard Analytical File (SAF) 5% sample claims data:** For the Medicare eligible population (including those age 65 and older and those younger than 65 who were eligible for Medicare due to disability), we used the Medicare Standard Analytical File 5% sample claims data

in year 2023 (the latest available at the time of this analysis). The Medicare SAF 5% data includes both institutional (inpatient, outpatient, skilled nursing facility, hospice, and home health agency) and non-institutional (physician, advanced practice provider, therapy, and durable medical equipment providers) claim types for Medicare fee-for-service (FFS) beneficiaries.

- **Transformed Medicaid Statistical Information System (T-MSIS) data:** We also obtained the 2022 Medicaid T-MSIS analytic files from the Centers for Medicare & Medicaid Services (CMS) via the Research Data Assistance Center (ResDAC). Medicaid data may be particularly important in capturing information for diverse patient populations [22, 23]. In addition, Medicaid claims data include services billable to Medicaid, such as long-term care, home health, rehabilitation facility, as well as some care partner services, which are not billable, thus not included, in other payer databases.

Additionally, we used other data sources to support our estimates of national prevalence and economic burden. These sources included:

- **U.S. Census data:** we used the American Community Survey and the Current Population Survey Annual Social and Economic Supplements (2020-2024) to construct population strata and estimate average earnings
- **Centers for Disease Control and Prevention Wide-ranging Online Data for Epidemiologic Research (CDC WONDER):** we used the CDC WONDER Multiple Cause of Death files (2022-2023) to estimate premature death due to PD.

A.2. Primary Data Collection – 2024 PD and Related Disorders Impact Survey

In conducting its previous study of the economic burden of PD in the U.S. in 2017 [5], Lewin developed the 2017 Financial and Social Impact Survey (2017 PD Impact Survey). This survey included 40 questions in several key domains, including: 1) health status, disease history and severity of PD; 2) demographics, and insurance coverage of the PWP/DP/AP; 3) informal care partner profile and care partner roles and responsibilities; 4) employment status, productivity, and income of the individual living with PD and their care partner(s); and 5) non-medical costs. Data collected via this survey characterized and quantified the disease impact and care partner burden to better illustrate the societal burden of PD. The 2017 PD Impact survey provided valuable data on the economic burden experienced by people with PD and their care partners, capturing key variables such as job loss, reduced working hours, caregiving costs, and transportation expenses. However, the survey was not comprehensive in covering non-medical costs (e.g., legal or financial planning costs), nor did it extensively capture data on the experience of care partners and the associated burden. Furthermore, it did not clearly distinguish PD and AP diagnoses, which is a critical matter in understanding the full spectrum of parkinsonism-related costs. We updated the PD Impact Survey for 2024 to enrich the current study on economic burden of PD and AP. The updated survey (2024 PD and Related Disorders Impact Survey) captured more detailed insights on the financial and social burden of PD and AP and filled gaps in understanding non-medical costs and care partner burden.

Survey Design and Sampling. A pilot version of the 2024 PD and Related Disorders Impact Survey was created to test skip patterns and assess the respondent burden in terms of difficulty and time required to answer questions. Based on the feedback received from technical stakeholders and patient/care partner representatives, we optimized survey language and clarified or reduced reading difficulty levels. It was not feasible to construct a sample frame for the entire U.S. population with PD or AP. Therefore, we took convenience samples and deployed the survey via two distinct avenues. To mitigate potential bias resulting from our survey sample, we weighted survey responses to represent the U.S. population with PD and AP in 2024 across age- and gender-specific strata. The resulting final survey was programmed in Qualtrics by the Fox Insight study administration for distribution by the Michael J. Fox Foundation via the Fox Insight

observational clinical study and via patient organizations to the broader PD and AP communities (Parkinson's Foundation, Cure PSP, and American Parkinson Disease Association). The survey was available to participants for inclusion in this analysis through both instances from April 2025 to June 2025. A summary of survey response rates can be found in Appendix A. Supplemental Results, Survey Sample Characteristics, Exhibit A 32).

B. Estimating Prevalence and Incidence of Parkinson's Disease and Atypical Parkinsonism

We drew on multiple data sources to estimate prevalence and incidence of PD and AP, shown in Exhibit 3, to capture information across individuals with coverage from different payers (e.g., Medicare beneficiaries, privately insured, military members, Medicaid enrollees).

The primary sources for estimating prevalence of PD were MCBS and MEPS as these nationally representative data sources facilitate prevalence estimates for multiple types of insurance status and payer. Estimates of prevalence of PD in the Medicare enrollees (both older and younger than 65 years old) were captured in the MCBS data and the Medicare SAF 5% sample claims data. MEPS provided estimates of prevalence of PD in the privately insured (younger than 65 years old), other health plans (e.g., the military, Indian Health Service), and the uninsured. We complimented the MEPS PD prevalence estimates for the privately insured with estimates captured in the Optum dNHI data, which also provided estimates of incidence of PD and AP as well as prevalence of AP. Estimates of incidence and prevalence of PD and AP in the Medicaid population were captured in the T-MSIS files.

Exhibit 3. Source Populations for Estimating Prevalence and Incidence of PD and AP

Data source	Population				Prevalence		Incidence	
	Private	Medicare	Medicaid	Other ^Y Insurance Types	PD	AP	PD	AP
MCBS* (2022)		√			√			
MEPS [^] (2023)	√	√	√	√	√			
Medicare SAF 5% (2023)		√				√	√	√
Optum dNHI (2024)	√					√	√	√
Medicaid T-MSIS (2022)			√			√	√	√

*MEPS data are limited to 3-digit ICD-10 diagnosis codes and only permits identification of PD

[^]MCBS does not collect information on AP diagnoses, thus only permitting identification of PD

^YOther insurance includes Veterans Administration benefits, TRICARE, Indian Health Service, other health plans and uninsured.

B.1. Prevalence

Parkinson's Disease Prevalence. This study aimed to update our previous study by using the most recently available data, capturing AP cases, and including the Medicaid analysis [5]. For our previous study, we used the MEPS data to estimate PD national prevalence. MEPS is a reliable source for information on populations with other insurance types and status (e.g., Veterans Administration benefits or TRICARE, Indian Health Services, other health plans, and uninsured) so we estimated PD prevalence in MEPS. We estimated prevalence of PD using the most recent year of data available. Details on identification of PD in various data sources are in Exhibit 4.

Exhibit 4. Identification of Patients with Parkinson's Disease by Data Source

Diagnosis	ICD-10 Code(s)	Definition
MCBS	N/A	(a) Patient ever told had PD OR (b) Active diagnosis in facility data OR (c) Active diagnosis in long-term care data
MEPS	G20	(a) Clinical Classification Software Refined (CCS) grouping for Parkinsonism OR (b) ICD-10-CM diagnosis code G20

*Claims data sources include Optum dNHI, Medicare SAF 5%, and T-MSIS

^List of anti-PD drugs is in C., Exhibit; data sources that do not include pharmacy claims (i.e., Medicare SAF 5%) used (a) and (b)

Prevalence rates were calculated by population strata, i.e., age-group (18-49, 50-64, 65-74, ≥75), gender (male/female), race/ethnicity (non-Hispanic White, non-Hispanic Black, non-Hispanic other, Hispanic), and insurance (private, Medicare, Medicaid, and other). Prevalence rates of PD were derived for the Medicare eligible population using MCBS 2022 data and for the under 65 non-Medicare population using MEPS 2023. The size of the PD population was estimated using U.S. Census Bureau projections by age-gender-race-insurance strata for the year 2024.

Atypical Parkinsonism Prevalence. The MEPS data are limited by 3-digit ICD-10 diagnosis codes and does not allow identification of AP diagnoses of interest. Because MCBS and MEPS do not include AP diagnoses, we relied on administrative claims data sources to ascertain prevalence of AP diagnoses using ICD-10 codes (Exhibit 5). For privately insured adults we used Optum's dNHI administrative claims data, for Medicare beneficiaries we used the Medicare 5% sample analytic file, and for Medicaid beneficiaries we used the T-MSIS files. We also included diagnosis codes that correspond to AP diagnoses and other neurodegenerative conditions such as cortical basal degeneration (CBS) and multiple system atrophy (MSA). To be included in the source population for a given service year, enrollees had to be continuously enrolled in the health plan with both medical and pharmacy coverage for the entire calendar year, allowing for 60-day gap in enrollment.

Exhibit 5. Identification of Patients with Parkinson's Disease and Atypical Parkinsonism from Claims Data Sources

Diagnosis	ICD-10 Code(s)	Definitions
Parkinson's disease	G20.*	(a) ICD-10-CM Diagnosis code (Dx) G20.* on 1 inpatient (IP) claim OR (b) 2 outpatient (OP) claims on separates dates of service OR (c) 1 OP claim + 1 pharmacy claim for anti-PD specific medication^
Dementia with Lewy Bodies	G31.83	(a) Dx on 1 IP claim OR (b) 2 OP claims on separates dates of service OR (c) 1 OP claim + 1 pharmacy claim for anti-DLB specific medication^
Progressive Supranuclear Palsy (PSP)	G23.1	(a) Dx on 1 IP claim OR (b) 2 OP claims on separates dates of service
Multiple System Atrophy (MSA)	G23.2 G90.3	(a) Dx on 1 IP claim OR

Diagnosis	ICD-10 Code(s)	Definitions
		(b) 2 OP claims on separates dates of service
Corticobasal Degeneration/Syndrome (CBD/S)	G31.85	(a) Dx on 1 IP claim OR (b) 2 OP claims on separates dates of service
Vascular parkinsonism	G21.4	(a) Dx on 1 IP claim OR (b) 2 OP claims on separates dates of service
Parkinsonism not otherwise specified	G20.C	(a) Dx on 1 IP claim OR (b) 2 OP claims on separates dates of service

*Includes diagnosis codes that begin with these three digits.

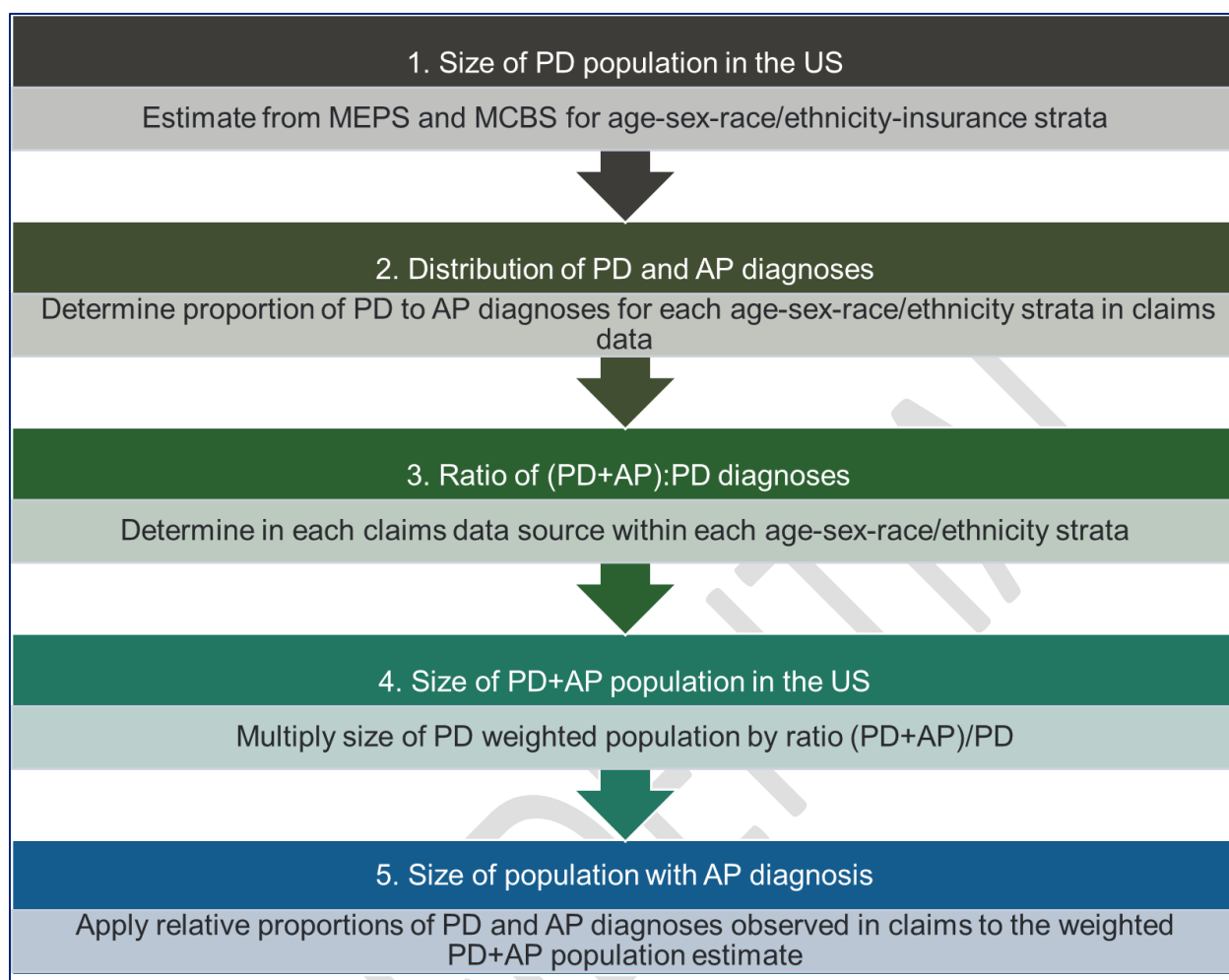
^Drug lists in Appendix C. Code Lists

Patients who met a definition for PD or AP were assigned to mutually exclusive cohorts based on the following hierarchical criteria:

- 1) If a patient met only one definition in the service year, we assigned the patient to respective cohort.
- 2) If a patient met only two definitions in the service year, and one of them was G20.C (Parkinsonism not otherwise specified), then we defaulted to other diagnosis (i.e., if met PD definition with codes other than G20.C then assigned to PD).
- 3) If a patient met multiple definitions in the service year, we used diagnosis in first position on outpatient claims with provider description/type neurology indicated.
- 4) If a patient met multiple definitions in the service year and provider description/type was not neurology, then we used diagnosis in first position on medical claims that was highest frequency
- 5) Exception for (4), if multiple definitions were met in the service year and there was a pharmacy claim for anti-DLB medication in the service year then we assigned the patient to DLB.

In each claims data source, we identified patients with PD or AP within each age-gender-race stratum. We calculated the ratio of the size of the total PD and AP population relative to the PD population and multiplied this ratio by the size of the PD population estimated for 2024 to get the size of the total PD and AP population for each age-gender-race strata (Exhibit 6). Within each stratum, we used the distribution of PD and AP diagnoses to estimate the number of people with each AP diagnosis of interest.

Exhibit 6. Illustration of Calculation Population Estimates of Atypical Parkinsonism Population



Comparison Group. A comparison population was identified with similar age, gender, insurance type, and race/ethnicity characteristics but without a PD or AP diagnosis. Our comparison group did not consider comorbid conditions as this was out of scope of this study. The specific characteristics we used to create the PD and comparison groups are:

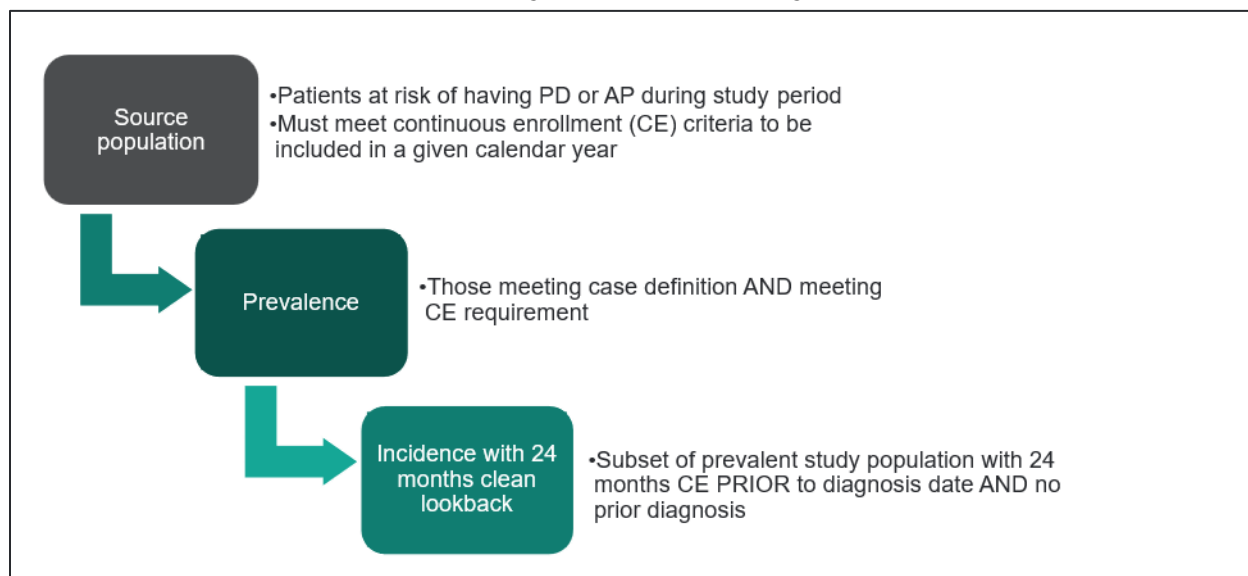
- Age group (18-49, 50-64, 65-74, ≥ 75)
- Gender (male, female)
- Insurance type (privately insured, Medicare, Medicaid, other)
- Race/ethnicity

B.2. Incidence

We estimated incidence of PD and AP in the three claims data sources (Optum dNHI, Medicare, and Medicaid). In estimating the disease incidence, we required a pre-diagnosis period to ensure a clean look-back by longitudinally tracking the continuously covered population in each data source.. Using multiple years of claims data, we identified enrollees who met the definition for PD or AP and had sufficient continuous enrollment pre-diagnosis to ascertain incident disease. Our approach is illustrated in Exhibit 7. In this example, patients are identified between 1/1/2022 and 12/31/2024 with the earliest diagnosis date in the identification period defined as the index date. To be considered an incident case, patients had to have at

least 24 months continuous enrollment pre-diagnosis and incident disease was confirmed by the absence of diagnosis codes during the pre-index (baseline) period.

Exhibit 7. Example Study Schema to Identify Incident PD or AP



C. Estimating Direct Medical Costs Attributable to Parkinson's Disease and Atypical Parkinsonism

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

Healthcare Resource Use Analysis. To quantify direct medical costs, first we estimated health care utilization from multiple payers using the most recent data available from Optum's dNHI administrative claims data (2024), Medicare SAF 5% (2023), Medicaid T-MSIS (2022), and MCBS data (2022). We captured the amounts paid by payers and patients from administrative claims data. All costs were adjusted for inflation to 2024 U.S. dollars using the medical component of the Consumer Price Index (CPI) from the Bureau of Labor Statistics [24]. We then estimated mean annual per patient direct medical costs by type of service for the following:

- Prevalent PD; those who met the definition for PD prevalence.
- Prevalent AP; those who met the definition for AP prevalence.
- Prior to formal diagnosis in incident PD
- Prior to formal diagnosis in incident AP
- Comparison group of controls without diagnosis of PD or AP

We estimated the annual per capita medical costs for each type of the following healthcare services separately:

- Non-acute institutional care (e.g., post-acute and long-term care, skilled nursing facility, rehabilitation facility, hospice)
- Inpatient (acute inpatient hospital, critical access hospital)
- Hospital outpatient (e.g., emergency department, urgent care, end-stage renal disease treatment facility, and ambulance)
- Office visits and ambulatory care (e.g., physician or clinic office visits, telehealth, physical therapy, occupational therapy, home-based care, laboratory facility, ambulatory surgery, and other unlisted facilities)
- Durable medical equipment
- Prescription medications (Optum dNHI, T-MSIS and MCBS only; not available in the Medicare SAF 5%)

In order to estimate the excess medical costs attributable to PD and AP, we calculated the attributable difference in medical costs between those diagnosed with PD or AP and a same age, gender, race/ethnicity and insurance (but not same comorbid conditions) comparison group without PD or AP.

Estimate Costs Prior to Formal Diagnosis. In addition to estimating medical costs in the population with prevalent PD and AP, we also assessed direct medical costs of PD and AP before formal diagnosis. First, we identified newly diagnosed patients with PD and AP in claims data (Exhibit 7). Once identified, the pre-diagnosis period was defined by determining the date of the first diagnosis and then examining healthcare claims from a clean lookback period (e.g., 24 months prior without any PD/AP diagnosis). Next, we assessed overall direct medical costs during this pre-diagnosis period. Finally, we compared the per capita costs in the 12 months prior to diagnosis to per capita costs of those without PD or AP diagnosis. A list of diagnoses captured in the pre-diagnosis period are listed in Appendix C, Exhibit C 3. Prodromal Diagnoses.

D. Estimating Indirect Costs

The economic burden of PD and AP is multifaceted. Lewin estimated three key dimensions of indirect costs attributable to PD and AP:

- Labor market employment-related earnings loss for PWPD/AP and their unpaid care partners;
- Productivity losses (employment-related and forgone social activities) for PWPD/AP and their unpaid care partners;
- Premature death-related future earnings loss for PWPD/AP.

In addition, we captured disability income and non-medical costs for PWPD/AP as well as the economic burden on care partners. Insights into the indirect and non-medical costs associated with PD and AP, were captured in the updated PD and Related Disorders Impact Survey for 2024, which included questions related to labor market participation, productivity loss for those in the labor force and not in the labor force, disability supplemental income, and key items of non-medical costs of PD and AP, such as paid care partners, home modifications, and transportation costs for patients with PD and AP. As the survey was based on a convenience sample, we calculated a survey weight for each respondent and reweighted the survey responses to represent the U.S. PD and AP population across age and gender strata.

D.1. Premature Death and Future Earnings Loss

Earnings Loss due to Premature Death. Future earnings loss due to premature deaths attributable to PD were estimated using CDC Wide-ranging ONline Data for Epidemiologic Research (CDC WONDER) Multiple Cause of Death file for 2022 and 2023 [25]. Patients with PD do not die from PD, but rather die with PD. The causes of death of PD patients are often listed as other factors, such as falls leading to serious injuries, pneumonia or other pulmonary conditions, bronchitis, lung infections, malignant neoplasms, heart

diseases, cerebral infarction, septicemia, among others [26, 27]. The mortality records that list PD both as the underlying cause of death as well as one of the multiple causes of death were examined and captured to the extent possible. Note that CDC WONDER uses 4-digit ICD-10 codes or group of codes for causes of death, which limits its ability to specifically identify AP and its subtypes. For some conditions, Parkinson's disease being one of them, cause of death may be underreported in CDC WONDER. Therefore, for the population aged 65 and older we captured deaths in each of the prevalent disease cohorts and the comparison group and estimated the excess deaths attributable to disease. Details calculation of death rates is described in Appendix E. Premature Death and Future Earnings Loss Analysis Plan.

We estimated future earnings loss due to premature death using similar methods as our previous study [5]. Briefly, future loss of earnings was computed based on estimated number of premature deaths and then multiplied by the present value (NPV) of future earnings for men and women by age group. The NPV approach incorporates information on average annual earnings, taking into account labor force participation rates and mortality rates, and assumes a productivity growth rate of 1% and a discount rate of 3%, a rate often used in public health studies [28, 29, 30]. We limited our calculation of earnings loss to adults 18-74 years of age.

D.2. Labor market Employment-Related Earnings Loss

Employment-Related Earnings Loss and Productivity Loss (Absenteeism, Presenteeism). Some studies have used MEPS or the National Health Interview Survey (NHIS) to estimate the impact of disease on the probability of employment, however these data do not have sufficient granularity to examine this type of productivity loss for the AP diagnoses of interest. Therefore, we leveraged the 2024 PD and Related Disorders Impact Survey with updated questions to capture self-reported workdays lost because of illness or other health problems (absenteeism) and how much work performance is hindered by health (presenteeism). Specifically, we estimated the impact of PD and AP on the probability of employment, combined with data on hourly wages to examine the effect of PD and AP on earnings' loss. Calculations for these cost components are detailed in Exhibit 8. Briefly, among those reported full- or part-time employment we estimated the earnings loss as the number of days' work missed multiplied by the average daily earnings and average number of months employed then annualized to the total loss. Similarly, we calculated presenteeism-related earnings loss as the number of days' work less productive multiplied by the average daily earnings and average number of months employed with an adjustment factor applied to reflect that an unproductive day is not equivalent to the total loss of whole day's value; the adjustment factor was calculated by comparing the annual earnings of the PD relative to non-PD group using MEPS data to reflect the overall productivity of PD as compared to non-PD.

Exhibit 8. Employment-Related Earnings Loss and Productivity Loss Cost Calculations

Cost Component	Calculation
Absenteeism	Calculated as the number of days' work missed in an average month <i>multiplied by</i> average number of months employed over past 12 months <i>multiplied by</i> average daily earnings among those whose current job status is part-time or full-time
Presenteeism	Calculated as the number of days' work less productive in an average month <i>multiplied by</i> average number of months employed over past 12 months <i>multiplied by</i> average daily earnings among those whose current job status is part-time or full-time <i>multiplied by</i> adjustment factor to reflect a partial days' worth of productivity

Cost Component	Calculation
Daily earnings	Calculated as the annual earnings reported in the 2024 PD and Related Disorders Impact Survey (using midpoint for respective category range) divided by # months employed in the past year divided by 30.25

Additional details on these calculations are in Appendix D. Equation Map for Calculating Indirect and Non-medical Costs from Survey.

D.3. Productivity Loss from Forgone Social Activities and Volunteering

One way of capturing this type of productivity loss uses the Volunteering and Civic Life Supplement of the Current Population Survey ([Volunteering and Civic Life \(census.gov\)](https://www.census.gov/data/tables/2014/other-population-subsamples/cps-2014-volunteering-and-civic-life-supplement.html)) to calculate the percentage of individuals who volunteer in a year and the average number of hours volunteered. However, these data do not allow us to distinguish PD and AP diagnoses, which could have different productivity impacts due to different manifestation and progression of symptoms. Therefore, we included similar questions about time spent volunteering in the 2024 PD and Related Disorders Impact Survey. The productivity loss of forgone social activities, or the social productivity reduction, was calculated as the percentage reduction in hours spent on the volunteer activity from before and after PD and AP start to have a major impact, which can be computed using the 2024 PD and Related Disorders Impact Survey. The social productivity reduction was then applied to the average hours each individual is expected to volunteer, based on their age and gender, and with the impact of PD and AP, to calculate the hours lost from volunteering activity due to PD and AP. The estimated hours lost due to PD and AP were then multiplied with the average value of each volunteer hour of \$34.8 as estimated by the Independent Sector to quantify the economic value of social productivity loss [31]. Additional details on these calculations are in Appendix D. Equation Map for Calculating Indirect and Non-medical Costs from PD and Related Disorders Impact Survey .

E. Disability Benefit Costs

From a policy perspective, it is important to capture the extent to which individuals transition to public programs and the potential cost to these public programs that can be attributed to the disease. For instance, the Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) are considered “transfer payments” (i.e., a cost to one person is a benefit to another person), and thus these cost components may provide insight into the government budgetary burden due to PD and AP. The 2024 PD and Related Disorders Impact Survey included questions on whether the PWPD/AP has received SSI, SSDI, or other types of disability income (OTDI) in the past 12 months. Based on the proportion of respondents with PD and AP, we estimated the average disability income due to PD and AP.

F. Estimating Non-Medical Costs and Out-of-Pocket Costs Not Covered by Insurance

The 2024 PD and Related Disorders Impact Survey included new questions to capture information on non-medical expenses incurred by the PWPD/AP and their household in the past 12 months, such as costs of legal and financial planning, hiring someone to take care of household chores, and out-of-pocket costs of long-term care or respite care (Exhibit 9). In addition, the survey captured information on out-of-pocket health-related costs not covered by insurance and paid for by PWPD/AP, such as: over-the-counter medications and supplements, supplies (e.g., adaptive clothing, feeding), durable medical equipment, therapeutic activities (e.g., gym membership, exercise classes), counseling for PWPD/AP or care partners, and expenses related to where a PWPD/AP resides and for how many months out of the past year including: adult outpatient rehab facility, hospice facility, nursing home, or skilled nursing facility.

Exhibit 9. Non-Medical and Out-of-Pocket Medical-Related Expenses Not Covered by Insurance and Paid for by PWP/DP

Cost Component	Expense Paid for by PWP/DP	Description
Non-medical costs	Paid daily non-medical care	Hiring someone (e.g., a professional, relative, or friend) to provide daily non-medical care
	Home modifications	Home purchase or modifications (e.g., building a ramp in place of steps to enter/exit home)
	One-time accessible home purchase	One-time costs incurred for moving or purchasing a residence necessary to meet care needs (e.g., moving company fees, closing costs to purchase an accessible home)
	Motor vehicle modification	Purchasing a special vehicle or purchasing/installing special equipment on a car or other motor vehicle
	Paid household help*	Hiring someone to do household chores/provide services other than patient care (e.g., shopping, meal preparation, delivery, house cleaning, gardening, taking care of other dependents, etc.)
	Increased transportation costs	Driving, taking taxis or rideshares to and from clinics, rehab facilities, visiting PWP/DP who live in nursing home, etc.
	Financial and legal planning*	Expenses related to financial and legal planning
	Respite for care partner*	Short-term break given to care partner (can take place inside or outside the home, including a health care facility, or adult day care)
Out-of-pocket costs (not covered by insurance)	Products	Over the counter medications and supplements
	Supplies	Adaptive clothing, feeding equipment, other supplies
	Medical equipment	Durable medical equipment
	Therapeutic activities	Gym, exercise classes, online classes
	Counseling	Education, psychotherapy, nutrition or dietitian for patient and care partners

*Non-medical cost components added to the 2024 PD and Related Disorders Impact Survey.

G. Future Prevalence and Cost Projections

We estimated the future size of the PD and AP population in the U.S. and estimated the total economic burden in current (2024) dollars. We used U.S. Census age and gender specific population projections to account for population growth and demographic shifts from 2025 to 2045. We then carried forward the age-gender specific prevalence rates of PD and AP in 2024 and applied them as fixed prevalence rates to obtain the estimated size of the population with PD and AP in future years. The projected prevalence based on this approach factors in population growth and demographic changes (e.g., age and gender distribution) in population assuming current incidence and mortality rates remain constant during the same period.

To project the total economic burden of PD and AP from 2025 through 2045, we multiplied the ratio of the total projected prevalence in the current year to the previous year by the current year's economic burden.

For example, to estimate the 2025 economic burden, we multiplied the 2025/2024 total projected prevalence by the 2024 total economic burden.

Input Data. Accurate projections of future prevalence and PD burden rely on high quality data input. We relied on a combination of original analysis of claims data and the PD and Related Disorders Impact Survey to obtain the set of input data needed for each parameter required in the projection model. Exhibit 10 below describes the definitions of the key data input parameters and the data source for each parameter. We describe some of the important analytical considerations in the subsections below.

Exhibit 10. Future impact of Parkinson's disease projection model data input

Input Parameters	Definition	Data Source
U.S. population	Projected U.S. population by age, gender and year (2024-2045)	Obtained from U.S. Census population projections.
Prevalence	Number of existing PWP/DP/APs in 2024	Original analysis of Medicare Current Beneficiary Survey (MCBS) and Medical Expenditure Panel Survey (MEPS) and Census population data.
Total economic burden	Direct, Indirect and Non-Medical Costs	Original analyses of PD and AP prevalence using Medical Expenditure Panel Survey (MEPS), Medicare Current Beneficiary Survey (MCBS), and Census population projection; combined with direct medical cost estimates using Optum dNHI administrative claims, Medicare Standard Analytical File 5% sample claims, Medicare Current Beneficiary Survey (MCBS), and the Impact of Parkinson's and Related Disorders Survey.

H. Care Partner Burden

Informal caregiving is a critical component of the healthcare landscape with significant costs to care partners and families. In addition to the impact of caregiving on workforce participation and productivity captured in our estimates of indirect costs, care giving can also have negative impacts on the financial, social, and physical health of the care partner themselves. To capture some of these non-intangible costs, we conducted analyses to describe the care partner experience using insights derived from the 2024 PD and Related Disorders Impact Survey. Specifically, we describe the composition of the care partner network in terms of number of care partners and their relationship(s) to the PWP/DP/AP. In addition, the new survey included questions about the physical, emotional, and financial impact of providing care for a PWP/DP/AP.

III. Results

A. Economic Burden of Parkinson's Disease and Atypical Parkinsonism in 2024

A.1. Prevalence of Parkinson's and Atypical Parkinsonism in 2024

The size of the population with PD or AP by population characteristics is shown in Exhibit 11. An estimated 1.2 million individuals, aged 18 years and older, in the U.S. have AP or PD in 2024. The prevalence of PD and AP increases with age, with the 65 and older persons representing the largest share (75%) of the PD and AP population. Males have a slightly higher prevalence than females, 0.57 percent and 0.35 percent respectively. The prevalence of PD or AP in non-Hispanic whites is 1.3 times the prevalence of the non-Hispanic black and four times that of the Hispanic populations with more than 910,000 in the White subgroup (75% of total PD or AP population). The vast majority (87%) of the PD or AP population are eligible for Medicare coverage.

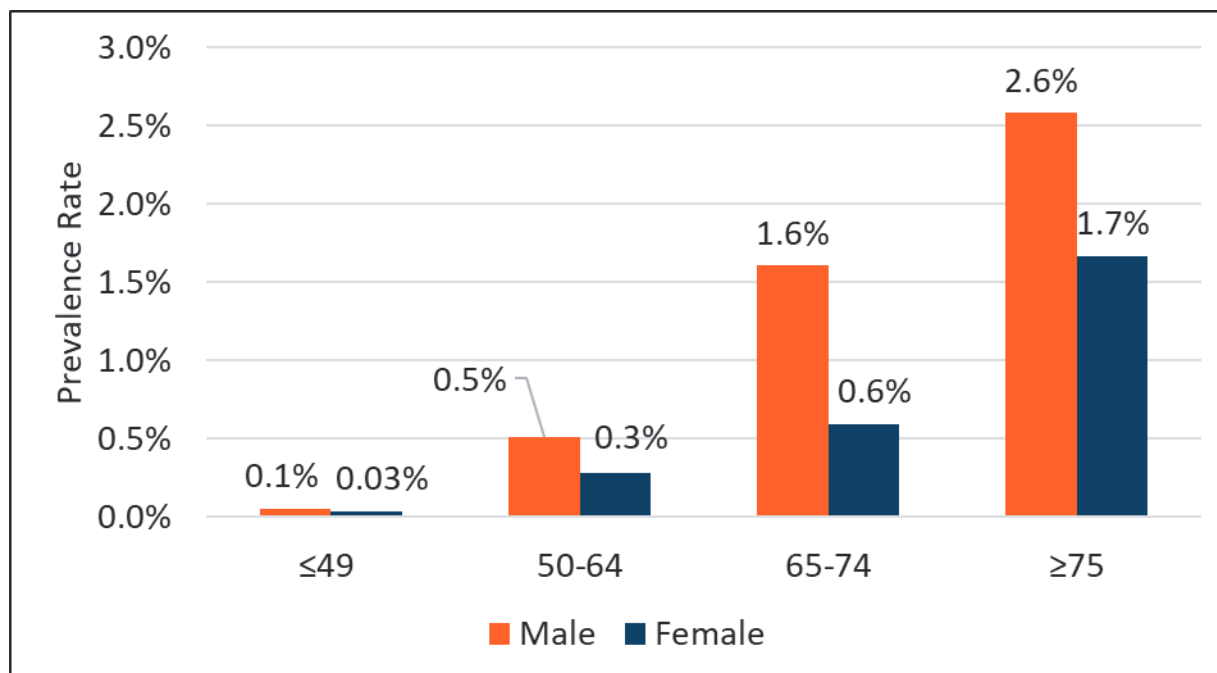
Exhibit 11. Parkinson's Disease and Atypical Parkinsonism Prevalence by Population Characteristics

	No. of Persons Estimated to Have PD or AP	Population	Prevalence
Age Group			
18-49	56,816	141,792,556	0.04%
50-64	240,838	61,660,017	0.39%
65-74	376,698	35,223,309	1.07%
≥75	539,611	26,298,663	2.05%
Gender			
Male	744,131	130,227,394	0.57%
Female	469,832	134,747,151	0.35%
Race/Ethnicity			
NH White	914,204	161,154,757	0.57%
NH Black	138,181	31,955,514	0.43%
Other	62,358	24,560,303	0.25%
Hispanic	99,363	47,303,971	0.21%
Insurance			
Private	105,803	138,862,094	0.1%
Medicare	1,056,543	73,280,221	1.4%
Medicaid	25,427	28,432,466	0.1%
Other insurance*	26,190	24,399,765	0.1%
Overall	1,213,963	264,974,545	0.5%

Source: Lewin analyses of 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2024.

*Other insurance includes other insurance not listed above such as Indian Health Services, military, and uninsured.

Among the population with PD and related disorders, approximately 10% have an AP diagnosis, ranging from 6.8% among males 50-64 years to 11.7% among females 18-49 years (Exhibit 12). The prevalence of PD and AP by population characteristics are presented in Appendix A. Supplemental Results, Exhibit A 1 and Exhibit A 17, respectively; detailed prevalence estimates for each AP diagnosis are presented in Appendix F. Landscape Formatted Exhibits, Exhibit F 1. Among U.S. adults in 2024, an estimated 1.09 million individuals have PD and approximately 120,000 have AP. The prevalence of PD and AP increases with age, with the 65 and older persons representing the largest share (74%) of the PD population. Males have a higher prevalence than females, 0.52% and 0.31%, respectively. The prevalence rate of PD in non-Hispanic whites is higher than the prevalence rate of the non-Hispanic black and double that of the Hispanic populations with more than 800,000 in the White subgroup (75% of total PD population). The majority (86%) of the PD population are eligible for Medicare coverage.

Exhibit 12. Parkinson's Disease and Atypical Parkinsonism Prevalence Rates in 2024 by Age Group and Gender

Source: Lewin analyses of 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2024.

A.2. Direct Medical Costs Attributable to Prevalent Parkinson's and Atypical Parkinsonism

The direct medical cost of Parkinson's and atypical parkinsonism by age and gender are shown in Exhibit 13. Per capita excess medical cost attributable to PD and AP was highest for those under age 50 years relative to older age groups. total excess costs for this age group only accounted <7% of the total excess costs. In contrast, those ages 65 and over account for nearly 74% of total excess costs.

Exhibit 13. Total (in Billions) and Per Capita Direct Medical Cost Attributable to Parkinson's Disease and Atypical Parkinsonism by Age and Gender

Gender and Age Group	Total Excess Medical Cost*		Per Capita Excess Cost due to PD or AP (\$)
	Excess Cost (in Billion \$)	Percentage of Total	
Males			
18-49 years	\$0.87	4%	\$23,900
50-64 years	\$3.40	14%	\$22,050
65-74 years	\$5.26	22%	\$19,717
≥75 years	\$4.94	21%	\$17,234
Females			
18-49 years	\$0.55	2%	\$26,770
50-64 years	\$1.47	6%	\$17,006
65-74 years	\$2.01	8%	\$18,258
≥75 years	\$5.33	22%	\$21,068

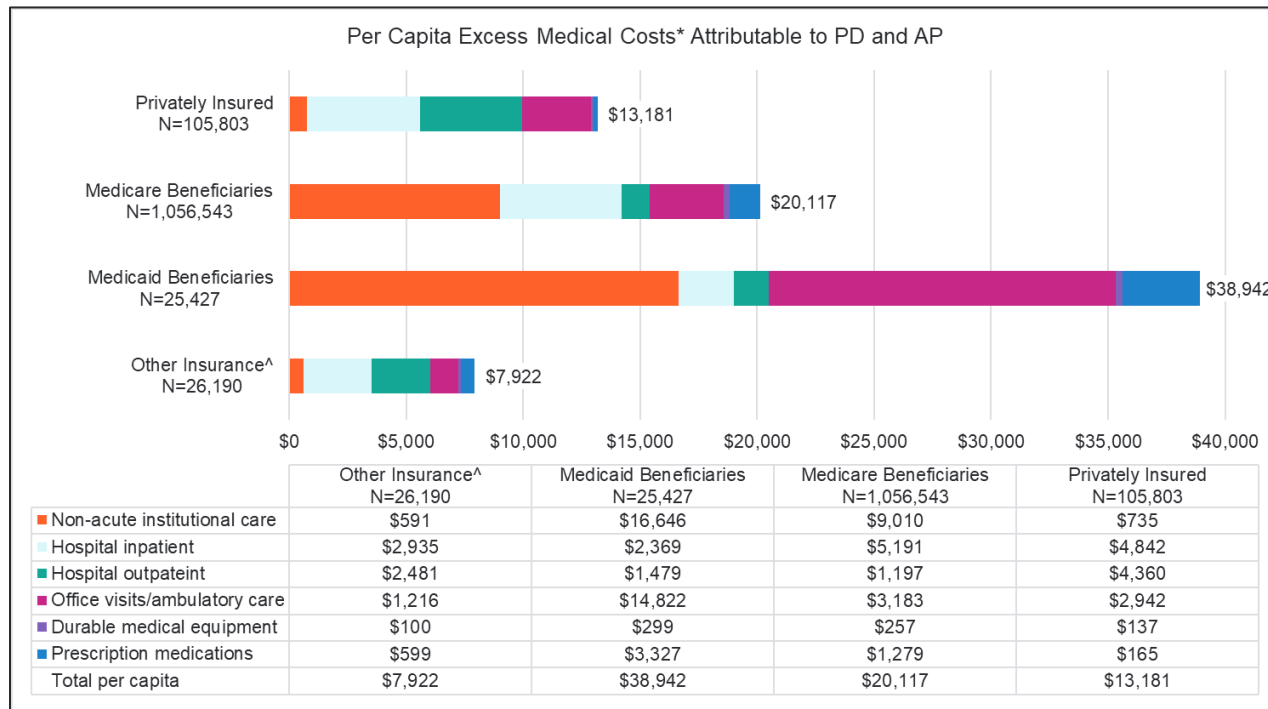
Gender and Age Group	Total Excess Medical Cost*		Per Capita Excess Cost due to PD or AP (\$)
	Excess Cost (in Billion \$)	Percentage of Total	
Overall	\$23.83		\$19,627

Source: Lewin analyses of PD and AP prevalence using 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2024; combined with direct medical cost estimates using 2024 Optum dNHI administrative claims, 2023 Medicare Standard Analytical File 5% sample claims, 2022 Transformed Medicaid Statistical Information System (T-MSIS), and 2022 Medicare Current Beneficiary Survey (MCBS).

*CPI adjusted to 2024 USD.

The analysis of excess direct medical costs attributable to PD and AP by type of service and insurance type is shown in Exhibit 14. Excess per capita costs attributable to PD and AP were greatest for Medicaid beneficiaries (\$38,942) and Medicare beneficiaries (\$20,117) primarily driven by non-acute institutional care (\$9,010 and \$16,646, respectively) and office visits/ambulatory care for Medicaid beneficiaries. This is primarily due to average per capita medical costs in the comparison group of Medicaid beneficiaries without PD or AP having very low costs (Appendix A. Supplemental Results, Exhibit A 31 and Appendix F. , Exhibit F 2), resulting in greater attributable costs relative to other insurance types. We observed higher average per capita costs for PWP/DP with Medicaid, which may be due, in part, to greater proportion of Medicaid beneficiaries with PD or AP meeting requirements for disability and receiving disability benefits (24% of PWP/DP compared with 8% of comparison group, data not shown). Research by the Kaiser Family Foundation has shown that Medicaid beneficiaries with disabilities have the highest healthcare system utilization among all categories of Medicaid enrollees [32]. Relative to other types of service, hospital inpatient and hospital outpatient were the most costly for the privately insured (\$4,842 and \$4,360, respectively) and other insurance types (\$2,935, and \$2,481, respectively).

Exhibit 14. Per Capita Direct Medical Cost* Attributable to PD and AP by Type of Service and Insurance Type



Source: Lewin analyses of PD and AP prevalence using 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2024; combined with direct medical cost estimates using 2024 Optum dNHI administrative claims, 2023 Medicare Standard Analytical File 5% sample claims, 2022 Transformed Medicaid Statistical Information System (T-MSIS), 2022 Medicare Current Beneficiary Survey (MCBS), and other costs (indirect, non-medical, disability benefit, and out-of-pocket) from the 2024 Impact of Parkinson's and Related Disorders Survey.

*CPI adjusted to 2024 USD.

^Other insurance includes such as Indian Health Services, military, and uninsured.

Total excess direct medical costs by type of service and insurance type are shown in Exhibit 15. In total, excess medical costs for the Medicare eligible population summed to \$21.3 billion in 2024, compared with \$1.4 billion for the privately insured population of PWPD/AP, \$0.9 billion for the Medicaid eligible population, and \$0.21 billion for the population of PWPD/AP with other types of insurance.

Exhibit 15. Total (in Billions) Excess Direct Medical Cost* Attributable to PD and AP by Type of Service and Insurance Type

Total Excess Cost Attributable to PD and AP (in Billions)	Private	Medicare	Medicaid	Other Insurance^
Type of Service				
Non-acute institutional care	\$0.08	\$9.52	\$0.42	\$0.02
Hospital inpatient	\$0.51	\$5.48	\$0.06	\$0.08
Hospital outpatient	\$0.46	\$1.27	\$0.04	\$0.06
Office visits/ambulatory care	\$0.31	\$3.36	\$0.38	\$0.03
Durable medical equipment	\$0.01	\$0.27	\$0.01	\$0.00
Prescription medications	\$0.02	\$1.35	\$0.08	\$0.02
Overall	\$1.39	\$21.25	\$0.99	\$0.21

Source: Lewin analyses of PD and AP prevalence using 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2024; combined with direct medical cost estimates using 2023 Medicare Standard Analytical File 5% sample claims, 2023 Medicare Standard Analytical File 5% sample claims, 2022 Transformed Medicaid Statistical Information System (T-MSIS), 2022 Medicare Current Beneficiary Survey (MCBS), and other costs (indirect, non-medical, disability benefit, and out-of-pocket) from the 2024 Impact of Parkinson's and Related Disorders Survey. *CPI adjusted to 2024 USD.

^Other insurance includes such as Indian Health Services, military, and uninsured.

A.3. Indirect Costs of Parkinson's Disease and Atypical Parkinsonism

We estimated total indirect and non-medical costs of PD and AP as \$54.3 billion in 2024. Indirect costs included earnings loss, reduced employment, and labor market productivity losses (absenteeism and presenteeism) as described below. Per capita indirect costs for PWPD/AP and care partner were \$44,694 (Exhibit ES 5).

Premature Death and Future Earnings Loss

The estimated number of premature deaths attributable to PD and AP are shown in Exhibit 16. In summary, we estimated a total of 18,096 premature deaths. This lower estimate of premature deaths due to PD/AP (18,069 in the current study compared to 23,393 in the previous study) could be related to the high mortality of PWPD/AP during the COVID-19 pandemic that resulted in lower premature deaths during the study period. Previous research found that age-adjusted PD-related mortality rates increased since 1999, peaking at 119.6/100,000 in 2020 exceeding projected mortality [33]. In addition, COVID-19-related mortality among those with severe neurologic conditions was nearly 3-fold higher (24.7%, estimated 25,964 excess deaths) compared with all-cause mortality rates during COVID-19 (7.9%) and pre-COVID-19 (6.8%) [34].

Exhibit 16. Estimated Number of Premature Deaths Associated with Parkinson's disease and Atypical Parkinsonism in 2024

Gender and Age Group	PD/AP Death Rate	Non-PD/AP Death Rate	Difference in Rates (PD/AP - non-PD/AP)	Estimated Number of Premature Deaths for PD/AP
Males				
18-49 years	0.7%	0.3%	0.5%	179
50-64 years	2.4%	1.0%	1.5%	2,422

Gender and Age Group	PD/AP Death Rate	Non-PD/AP Death Rate	Difference in Rates (PD/AP - non-PD/AP)	Estimated Number of Premature Deaths for PD/AP
65-74 years	6.8%	2.6%	4.3%	9,233
Females				
18-49 years	1.1%	0.1%	1.0%	211
50-64 years	3.3%	0.6%	2.7%	2,338
65-74 years	5.9%	1.7%	4.2%	3,713
Overall				18,096

Source: Lewin analyses of 2022-2023 CDC Wonder and 2023 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.

The estimated present value of future earnings loss for each age and gender group under age 75 is shown in Exhibit 17. The average present value of future earnings per death is lower for each subsequently older age group in both males and females. However, due to differences in labor force participation rates and earnings, the estimated present value of future earnings is lower for females compared with males. In total, the estimated net present value of lost earnings attributable to premature death in 2024 is estimated to be \$3.1 billion.

Exhibit 17. Estimated Net Present Value of the Future Earnings Loss for Premature Deaths Associated with Parkinson's Disease and Atypical Parkinsonism

Gender and Age Group	Estimated Number of Premature Deaths	Estimated Present Value of Future Earnings/Death (\$*)	Estimated NPV (in Billion \$)
Males			
18-49 years	179	\$1,195,551	\$0.21
50-64 years	2,422	\$428,159	\$1.04
65-74 years	9,233	\$69,940	\$0.65
Females			
18-49 years	211	\$1,020,494	\$0.22
50-64 years	2,338	\$353,358	\$0.83
65-74 years	3,713	\$49,481	\$0.18
Overall	18,096		\$3.12

Source: Lewin analyses of 2022-2023 CDC Wonder and 2023 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.

*CPI adjusted to 2024 USD.

Labor Market Employment-Related Earnings Loss

Among PWPD/AP and care partners under age 75, 12% of PWPD/AP indicated that PD or AP played a role in their decision to stop working and 13% of care partners reported that their care responsibilities played a role in their decision to stop working (Exhibit 18). The total estimated earnings loss due to forced early retirement in 2024 is estimated to be \$6.75 billion for PWPD/AP and \$1.72 billion for their care partners. Among care partners, females ages 65 to 74 were the most likely to report leaving the workforce due their care responsibilities and thus incurred the highest earnings loss relative to males and to other age groups.

Exhibit 18. Estimated Labor Market Earnings Loss (in Billions) due to Parkinson's Disease and Atypical Parkinsonism Related Unemployment

Gender and Age Group	PWPD/AP		Care Partner	
	Percentage Retired and Stopped Working due to PD/AP	Total Earnings Loss (in Billion \$)*	Percentage Retired and Stopped Working due to PD/AP	Total Earnings Loss (in Billion \$)*
Males				
18-49 years	12%	\$0.26	--	\$0.00
50-64 years	23%	\$2.19	24%	\$0.10
65-74 years	21%	\$2.49	13%	\$0.22
Females				
18-49 years	5%	\$0.05	3%	\$0.19
50-64 years	29%	\$1.20	17%	\$0.34
65-74 years	19%	\$0.56	23%	\$0.86
Overall	12%	\$6.75	13%	\$1.72

Source: Primary data collected through the PD and Related Disorders Impact Survey, combined with average earnings from Bureau of Labor Statistics, and PD and AP prevalence estimated by Lewin. PWPD/AP refers to people with Parkinson's disease inclusive of atypical parkinsonism.

*May not sum to Overall row due to rounding.

Labor Market Productivity Loss

Exhibit 19 shows the percentage of PWPD/AP and their unpaid care partners who reported working in the past 12 months. In general, the likelihood of reporting labor market participation decreases with age for both PWPD/AP and their unpaid care partners. Based on our survey, the size of the female care partner population is larger than the male population for each age group (see Section III. D. Care Partner Burden).

Exhibit 19. Percentage of Persons with Parkinson's Disease or Atypical Parkinsonism and Unpaid Care Partners Employed in the Past 12 Months

Gender and Age Group	PWPD/AP		Care Partner	
	Total Population	% Employed	Total Population	% Employed
Males				
18-49 years	36,359	55%	8,311	--
50-64 years	154,350	43%	6,230	44%
65-74 years	266,632	10%	53,839	10%
≥75 years	286,790	4%	39,050	2%
Females				
18-49 years	20,457	56%	141,973	64%
50-64 years	86,489	32%	43,473	53%
65-74 years	110,066	8%	118,672	15%
≥75 years	252,821	4%	106,069	5%
Overall	1,213,963	15%	517,616	28%

Source: Primary data collected through the PD Impact Survey, combined with PD and AP prevalence estimated by Lewin. PWPD/AP refers to people with Parkinson's disease inclusive of atypical parkinsonism.

In general, productivity loss related to absenteeism was greater for male compared with female PWP/DP/AP while productivity loss related to absenteeism was greater for female compared with male care partners. While males under 50 years of age missed fewer work days compared with same age female PWP/DP/AP (3.7 and 6.1, respectively), the total annual cost of absenteeism is \$0.4 billion for each group (Exhibit 20). At the same time, on average, male and female PWP/DP/AP age 50 to 64 years missed roughly the same number of days work per month, but the total cost of absenteeism was more than three times greater for males in this age group due to greater number of PWP/DP/AP who were male age 50-64 years.. In contrast, because they outnumber male care partners, the total cost of absenteeism is greater for each age group among female care partners.

Exhibit 20. Productivity Loss Due (in Billions) to Parkinson's and Atypical Parkinsonism Related Absenteeism in 2024

Gender and Age Group	PWP/DP/AP		Care Partner	
	Average No. of Workdays Missed per Month	Total Annual Absenteeism Cost (in B\$)*	Average No. of Workdays Missed per Month	Total Annual Absenteeism Cost (in Billions \$)*
Males				
18-49 years	3.7	\$0.43	--	\$0.00
50-64 years	4.1	\$1.63	5.6	\$0.09
65-74 years	2.9	\$0.34	6.3	\$0.12
≥75 years	4.8	\$0.28	10.0	\$0.02
Females				
18-49 years	6.1	\$0.43	8.3	\$2.57
50-64 years	4.0	\$0.51	6.6	\$0.61
65-74 years	2.2	\$0.08	4.0	\$0.34
≥75 years	1.3	\$0.06	6.5	\$0.09
Overall	3.8	\$3.77	7.3	\$3.84

Source: Primary data collected through the 2024 PD Impact Survey, combined with PD and AP prevalence estimated by Lewin. PWP/DP/AP refers to people with Parkinson's disease inclusive of atypical parkinsonism.

*May not sum to Overall row due to rounding.

We estimated earnings loss related to absenteeism as the number of days' work less productive multiplied by average daily earnings and adjusted to reflect that only a portion of a reported day less productive was considered a loss. As shown in Exhibit 21, PWP/DP/AP under 65 years of age were less productive on more than 10 days per month on average. On average, PWP/DP/AP felt less productive 10.7 days per month and care partners 14.8 days per month for total annual costs of presenteeism of \$3.3 and \$2.4 billion, respectively.

Exhibit 21. Estimated Productivity Loss Due (in Billions) to Parkinson's and Atypical Parkinsonism Related Presenteeism in 2024

Gender and Age Group	PWP/DP/AP		Care Partner	
	Average No. of Workdays Missed	Total Annual Presenteeism Cost (in Billions \$)*	Average No. of Workdays Missed	Total Annual Presenteeism Cost (in Billions \$)*
Males				

Gender and Age Group	PWPD/AP		Care Partner	
	Average No. of Workdays Missed	Total Annual Presenteeism Cost (in Billions \$)*	Average No. of Workdays Missed	Total Annual Presenteeism Cost (in Billions \$)*
18-49 years	13.1	\$0.47	--	\$0.00
50-64 years	11.7	\$1.46	9.5	\$0.05
65-74 years	7.0	\$0.25	15.8	\$0.09
≥75 years	10.1	\$0.19	8.3	\$0.01
Females				
18-49 years	11.6	\$0.25	16.8	\$1.61
50-64 years	12.6	\$0.50	13.2	\$0.37
65-74 years	6.4	\$0.07	7.8	\$0.21
≥75 years	4.8	\$0.07	12.8	\$0.06
Overall	10.7	\$3.26	14.8	\$2.39

Source: Primary data collected through the 2024 PD Impact Survey, combined with PD and AP prevalence estimated by Lewin. PWPD/AP refers to people with Parkinson's disease inclusive of atypical parkinsonism.

*May not sum to Overall row due to rounding.

Productivity Loss from Forgone Social Activities

We estimated the impact of PD and AP on social productivity for PWPD/AP and their unpaid care partners based on the individual survey respondent's ability to participate in the following voluntary activities before and after diagnosis: performing voluntary or charity work; providing help to family, friends or neighbors; or participating in political or community organizations. Exhibit 22 shows the impact of diagnosis and care duties on social productivity for PWPD/AP and their unpaid care partners. A diagnosis of PD or AP leads to a 50-70% reduction in an individual's ability to participate in voluntary activities with an estimated total annual social productivity loss of approximately \$1 billion for PWPD/AP and \$0.3 billion for care partners.

Exhibit 22. Estimated Social Productivity Loss (in Billions) Due to Parkinson's Disease and Atypical Parkinsonism in the Past 12 Months

Gender and Age Group	PWPD/AP Social Productivity				Care Partner Social Productivity			
	Volunteered, %	Mean Change in Hours	Change in Hours, %	Total Annual Loss (in Billion \$)^	Volunteered, %	Mean Change in Hours	Change in Hours, %	Total Annual Loss (in Billion \$)^
Males								
18-49	55%	9.3	71%	\$0.06	NA*	--	--	\$0.00
50-64	23%	7.6	65%	\$0.12	44%	3.8	40%	\$0.01
65-74	25%	4.1	58%	\$0.27	11%	9.5	60%	\$0.02
≥75	18%	5.3	53%	\$0.18	2%	NA*	--	\$0.00
Females								
18-49	29%	5.5	47%	\$0.01	58%	8.5	50%	\$0.16
50-64	28%	8.6	68%	\$0.08	52%	6.6	50%	\$0.05
65-74	28%	4.3	67%	\$0.13	15%	3.8	49%	\$0.05

Gender and Age Group	PWPDP/AP Social Productivity				Care Partner Social Productivity			
	Volunteered, %	Mean Change in Hours	Change in Hours, %	Total Annual Loss (in Billion \$)^	Volunteered, %	Mean Change in Hours	Change in Hours, %	Total Annual Loss (in Billion \$)^
≥75	20%	3.4	72%	\$0.24	4%	6.3	49%	\$0.01
Overall	24%	5.4	63%	\$1.07	19%	6.0	49%	\$0.31

Source: Lewin's analysis of the Current Population Survey Volunteer Supplement (2023), combined with primary data collected through the 2024 PD and Related Disorders Impact Survey, and PD and AP prevalence estimated by Lewin. PWPDP/AP is Person with Parkinson's disease inclusive of atypical parkinsonism.

*Due to small cell sizes for age-gender stratum reporting volunteer hours, we are unable to estimate change in volunteer hours.

^May not sum to overall row due to rounding.

A.4. Non-Medical Costs of Parkinson's Disease and Atypical Parkinsonism

A.5. Disability Benefit Costs

Among PWPDP/AP, approximately 5% reported receiving supplemental security income (SSI), 10% received social security disability income (SSDI), and 10% reported receiving other types of disability income (OTDI) as shown in Exhibit 23. In total, in 2024 disability benefit costs came to over \$8 billion, with those under 75 receiving the largest share.

Exhibit 23. Estimated Disability Benefit Cost (in Billions) Received by Persons with Parkinson's or Atypical Parkinsonism in the Past 12 Months

Gender and Age Group	% 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 Billions \$)
Males							
18-49 years	6%	\$11,604	9%	\$11,830	29%	\$45,101	\$0.53
50-64 years	6%	\$19,130	27%	\$24,407	18%	\$42,615	\$2.40
65-74 years	3%	\$19,948	13%	\$20,255	9%	\$46,479	\$1.92
≥75 years	5%	\$12,526	2%	\$13,234	11%	\$24,724	\$1.02
Females							
18-49 years	12%	\$12,852	18%	\$11,022	8%	\$22,818	\$0.11
50-64 years	8%	\$12,325	28%	\$21,950	15%	\$42,085	\$1.15
65-74 years	8%	\$15,778	5%	\$17,836	3%	\$34,464	\$0.36
≥75 years	6%	\$15,236	2%	\$6,501	5%	\$39,119	\$0.79
Overall	5%	\$15,343	10%	\$20,406	10.2%	\$38,111	\$8.28

Source: Primary data collected through the 2024 PD and Related Disorders Impact Survey, combined with PD prevalence estimated by Lewin.

*Annual other types of disability income (OTDI).

A.6. Non-Medical Costs and Out-of-Pocket Expenses Not Covered by Insurance

We asked survey respondents how much they spent, that they otherwise would not have spent, to hire someone to provide daily care for PWP/DP/AP in the past 12 months. Overall, 11% of PWP/DP/AP reported hiring someone to provide daily care or assistance in 2024 (Exhibit 24). In general, female PWP/DP/AP were more likely to report hiring someone for paid daily care compared with males in the same age group. The average annual expense for paid daily care per PWP/DP/AP was \$15,735 in 2024 with a total cost of paid daily care for the population with PD and AP of \$2.1 billion.

Exhibit 24. Estimated Paid Daily Non-Medical Care Expenses (in Billions) Due to Parkinson's Disease or Atypical Parkinsonism

Gender and Age Group	% of PWP/DP/AP Who Hired Someone to Provide Daily Care in the Past 12 Month	Average Expense per User (\$)	Total Cost of Paid Non-Medical Care (in Billion \$)
Males			
18-49 years	11%	\$1,925	\$0.01
50-64 years	8%	\$9,285	\$0.11
65-74 years	4%	\$3,795	\$0.04
≥75 years	13%	\$15,783	\$0.58
Females			
18-49 years	23%	\$18,194	\$0.09
50-64 years	17%	\$17,729	\$0.26
65-74 years	12%	\$16,007	\$0.21
≥75 years	16%	\$21,010	\$0.84
Overall	11%	\$15,735	\$2.13

Source: Primary data collected through the 2024 PD and Related Disorders Impact Survey, combined with PD prevalence estimated by Lewin. PWP/DP/AP is people with Parkinson's disease inclusive of atypical parkinsonism.

Exhibit 25 shows the percentage of PWP/DP/AP who incurred other non-medical costs in 2024. Nearly 20% reported expenses for home modifications (e.g., building a ramp to enter home), 10% reported purchasing a special vehicle or installing special equipment on a car or other motor vehicle. Approximately 6% reported one-time costs associated with the purchase of a home necessary to meet the care needs of the PWP/DP/AP (e.g., moving company fees, closing costs). In addition to paid daily care, nearly 30% reported expenses for non-medical household help (e.g., cleaning, shopping, meal prep, dependent care). More than half reported expenses related to products, medical equipment and activities. The estimated total non-medical costs for the PD and AP population summed to \$23.9 billion. The average non-medical expenses by age and gender are shown in Appendix F. Landscape Formatted .

Exhibit 25. Estimated Non-Medical Costs and Out-of-Pocket Expenses Not Covered by Insurance (in Billions) Due to Parkinson's Disease and Atypical Parkinsonism in 2024

Non-Medical Cost Component	% With Expense	Average Expense per User (\$)	Total (in Billions \$)
Non-Medical Expenses			
Paid daily non-medical care	11.2%	\$15,735	\$2.13

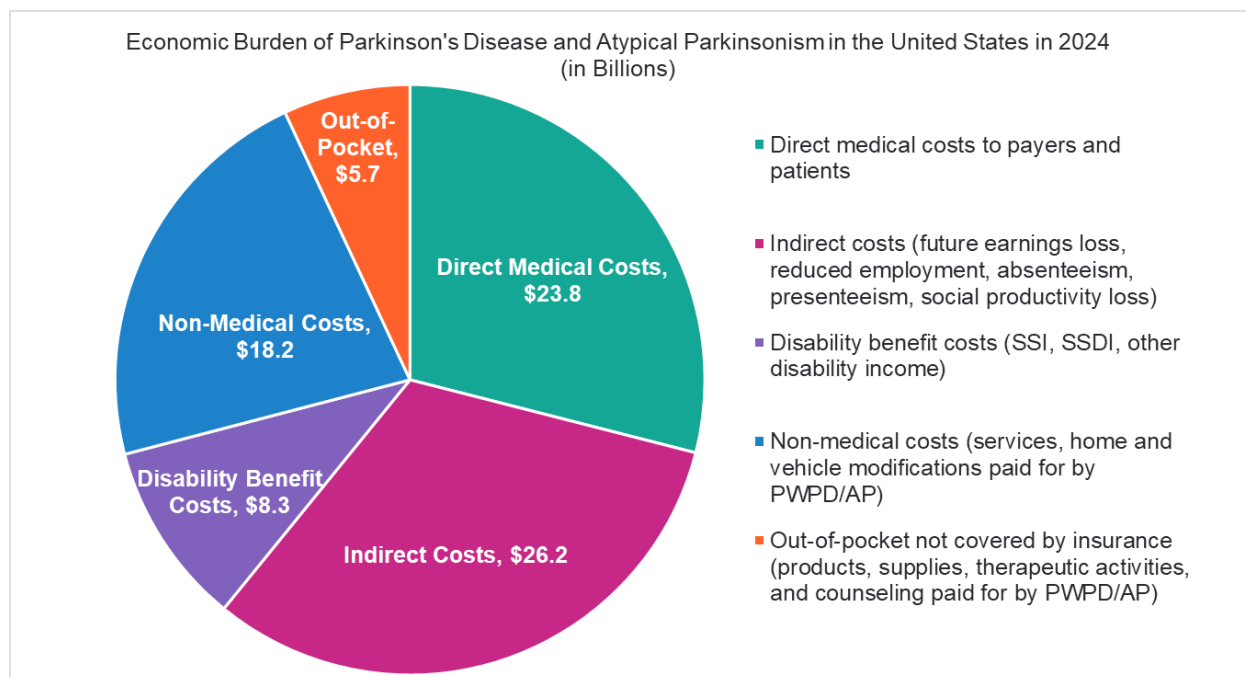
Non-Medical Cost Component	% With Expense	Average Expense per User (\$)	Total (in Billions \$)
Home modifications	19.3%	\$9,996	\$2.34
Motor vehicle modifications	10.4%	\$5,820	\$7.77
Other increased transportation costs	27.1%	\$557	\$0.18
Hiring someone to do household chores/provide services other than patient care	29.7%	\$11,168	\$4.02
One-time accessible home purchase	6.1%	\$105,538	\$0.74
Legal and financial services	20.3%	\$3,238	\$0.80
Respite for care partner	6.1%	\$2,574	\$0.19
Out-of-Pocket Expenses Not Covered by Insurance			
Products (over-the-counter and supplements)	61.3%	\$1,505	\$1.12
Supplies (e.g., adaptive clothing, feeding equipment)	27.1%	\$659	\$0.22
Medical equipment	52.5%	\$841	\$0.00
Therapeutic activities (e.g., gym, exercise classes, home exercise equipment)	50.6%	\$275	\$0.17
Counseling (patient education, psychotherapy, nutrition counseling)	20.8%	\$16,684	\$4.22
Total		\$19,683	\$23.90

Source: Primary data collected through the 2024 PD and Related Disorders Impact Survey, combined with PD prevalence estimated by Lewin.

A.7. Total Economic Burden of Parkinson's Disease and Atypical Parkinsonism in 2024

The estimated total economic burden of PD and AP in 2024 was \$82.2 billion, including \$23.8 billion in excess direct medical costs attributable to PD and AP, \$26.2 billion in indirect costs, \$8.3 billion in disability income, and \$23.9 billion in non-medical costs and out-of-pocket medical expenses not covered by insurance and paid for PWPD/AP (Exhibit 26). In total, excess direct medical costs account for 29% of the total economic burden, 93% of which is paid for Medicare and Medicaid; after accounting for SSI and SSDI benefit costs that equate to over \$25 billion borne by the government. Productivity losses account for 32% of the total economic burden, nearly a third of which is due to reduced employment and productivity of care partners. The remaining \$23.9 billion in expenses are borne by PWPD/AP and their care partners.

Exhibit 26. Total Economic Burden of Parkinson's Disease or Atypical Parkinsonism in the U.S. in 2024 (in Billions)



Source: Lewin analyses of PD and AP prevalence using 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2024; combined with direct medical cost estimates using 2024 Optum dNHI administrative claims, 2023 Medicare Standard Analytical File 5% sample claims, 2022 Transformed Medicaid Statistical Information System (T-MSIS), 2022 Medicare Current Beneficiary Survey (MCBS), and other costs (indirect, non-medical, disability benefit, and out-of-pocket) from the 2024 Impact of Parkinson's and Related Disorders Survey.

*CPI adjusted to 2024 USD.

Exhibit 27 details the total excess medical cost by age, gender, race/ethnicity, and insurance. Overall, the per capita excess direct medical costs attributable to PD and AP in 2024 was \$19,644. Per capita excess direct medical costs attributable to PD and AP were higher for those under 50 years of age compared with older age groups, for Hispanic compared with other race/ethnicities, and for Medicare beneficiaries compared with other insurance types. The Medicare eligible population accounted for almost 90% of total excess medical costs attributable to PD and AP in 2024. The population 65 years of age and older accounts for an estimated 74% of the total excess medical costs. The non-Hispanic white group represents 67% of the total medical costs. Non-acute institutional care and hospital inpatient care were the highest excess medical cost categories.

Exhibit 27. The Total (in Billions) and Per Capita Direct Medical Cost* of Parkinson's Disease and Atypical Parkinsonism in 2024 by Type of Service and Population Characteristics

	Total Excess Medical Cost* Attributable to PD or AP (in Billion \$)	Percentage of the Total	Per Capita Excess Cost(\$)
Age Group			
18-49	\$1.42	6%	\$24,934
50-64	\$4.87	20%	\$20,239
65-74	\$7.27	30%	\$19,290

	Total Excess Medical Cost* (in Billion \$)	Attributable to PD or AP Percentage of the Total	Per Capita Excess Cost(\$)
≥75	\$10.27	43%	\$19,030
Gender			
Male	\$14.47	61%	\$19,448
Female	\$9.35	39%	\$19,910
Race/Ethnicity			
NH White	\$15.89	67%	\$17,379
NH Black	\$4.18	18%	\$30,234
Other	\$1.29	5%	\$20,612
Hispanic	\$2.48	10%	\$24,917
Insurance			
Private	\$1.39	6%	\$13,181
Medicare	\$21.25	89%	\$20,117
Medicaid	\$0.99	4%	\$38,942
Other Insurance^	\$0.19	1%	\$7,150
Type of service			
Non-acute Institutional Care	\$10.04	42%	\$8,267
Hospital Inpatient	\$6.13	26%	\$5,053
Outpatient	\$1.83	8%	\$1,507
Physician Office	\$4.08	17%	\$3,363
Durable Medical Equipment	\$0.30	1%	\$244
Prescription Medication	\$1.47	6%	\$1,210
Overall	\$23.85		\$19,644

Source: Lewin analyses of PD and AP prevalence using 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2024; combined with direct medical cost estimates using 2024 Optum dNHI administrative claims, 2023 Medicare Standard Analytical File 5% sample claims, 2022 Transformed Medicaid Statistical Information System (T-MSIS), and 2022 Medicare Current Beneficiary Survey (MCBS).

*CPI adjusted to 2024 USD.

^Other insurance includes other insurance not listed above such as Indian Health Services, military, and uninsured.

The estimated total indirect and non-medical costs of PD and AP was \$58.4 billion in 2024 (Exhibit 28). This includes \$17.9 billion for PWPDP/AP and an additional \$8.3 billion for their unpaid care partners in earnings loss, reduced employment, and productivity losses; of the \$26.2 billion indirect costs attributable to PD and AP, labor market productivity losses (absenteeism and presenteeism) were the largest categories. Of the \$23.9 billion in non-medical costs, the largest contributors were motor vehicle modifications, paid household help and counseling for PWPDP/AP and care partners. We also include \$8.3 billion in disability benefit costs for PWPDP/AP in 2024.

Exhibit 28. The Indirect and Non-Medical Costs* of Parkinson's Disease and Atypical Parkinsonism in 2024 by Cost Component

	Total Indirect and Medical Costs (in Billion \$)^			Per Capita (\$)		
	PWPDP/AP Loss	Care Partner Loss	PWPDP/AP & Care Partner	PWPDP/AP Loss	Care Partner Loss	PWPDP/AP & Care Partner
Indirect Costs						

	Total Indirect and Medical Costs (in Billion \$)^			Per Capita (\$)		
	PWPD/AP Loss	Care Partner Loss	PWPD/AP & Care Partner	PWPD/AP Loss	Care Partner Loss	PWPD/AP & Care Partner
Premature Death	\$3.12	NA	\$3.12	\$2,572	NA	\$2,572
Reduced Employment	\$6.75	1.72	\$8.46	\$5,553	\$1,411	\$6,970
Absenteeism	\$3.77	\$3.84	\$7.61	\$3,108	\$3,165	\$6,273
Presenteeism	\$3.26	\$2.39	\$5.65	\$2,682	\$1,972	\$4,653
Social Productivity Loss in Volunteer Work	\$1.07	\$0.30	\$1.38	\$883	\$266	\$1,150
Disability Income						
Supplemental security income (SSI)	\$1.00	NA	\$1.00	\$827	NA	\$827
Social security disability insurance (SSDI)	\$2.56	NA	\$2.56	\$2,107	NA	\$2,107
Other disability income	\$4.71	NA	\$4.71	\$3,882	NA	\$3,882
Non-Medical Costs						
Paid daily non-medical care	\$2.13	NA	\$2.13	\$1,756	NA	\$1,756
Home modifications	\$2.34	NA	\$2.34	\$1,926	NA	\$1,926
Motor vehicle modification	\$7.77	NA	\$7.77	\$6,399	NA	\$6,399
Other increased transportation expenses	\$0.18	NA	\$0.18	\$151	NA	\$151
Hiring someone to do household chores/provide services other than patient care	\$4.02	NA	\$4.02	\$3,313	NA	\$3,313
One-time accessible home purchase	\$0.74	NA	\$0.74	\$605	NA	\$605
Legal and financial services	\$0.80	NA	\$0.80	\$658	NA	\$658
Respite for care partner	\$0.19	NA	\$0.19	\$157	NA	\$157
Out-of-Pocket Expenses Not Covered by Insurance	\$1.12		\$1.12			
Products (over-the-counter and supplements)	\$0.22	NA	\$0.22	\$922	NA	\$922
Supplies (e.g., adaptive clothing, feeding equipment)	\$0.00	NA	\$0.00	\$179	NA	\$179
Therapeutic activities (e.g., gym, exercise classes, home exercise equipment)	\$0.17	NA	\$0.17	\$139	NA	\$139
Counseling (patient education, psychotherapy, nutrition counseling)	\$4.22	NA	\$4.22	\$3,478	NA	\$3,478
Overall	\$50.14	\$8.26	\$58.39	\$40,301	\$6,800	\$48,101

Source: Lewin analyses of 2024 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 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2024. PWPD/AP is Person with Parkinson's disease inclusive of atypical parkinsonism.

*All costs in 2024 USD.

^May not sum to Overall row due to rounding.

B. Costs Prior to Formal Diagnosis

B.1. Incidence of Parkinson's Disease and Atypical Parkinsonism

In order to estimate the medical costs prior to diagnosis with Parkinson's and atypical parkinsonism, we estimated incidence in three large administrative claims data sources. Incidence rates per 100,000 population in person years are shown in Exhibit 29. Incidence rates are substantially higher for those 65 years and older (234 per 100,000) compared with those under 65 (22 per 100,000), males compared with females, and non-Hispanic white compared with other race/ethnicity groups. Incidence rates for PD were 19 per 100,000 for under 65 and 193 per 100,000 for 65 and older (Appendix A. Supplemental Results, Exhibit A 16). Incidence rates for AP were 3 per 100,000 for under 65 years and 42 per 100,000 for 65 and older (Appendix A. Supplemental Results, Exhibit A 30).

Exhibit 29. Parkinson's and Atypical Parkinsonism Incidence per 100,000 by Age, Gender, Race/Ethnicity and Insurance Type

	Incident* Cases	Person years	Incidence per 100,000 Population Person years
Age 18 to 64 years	3,570	16,570,172	21.5
Gender			
Male	2,078	7,840,138	26.5
Female	1,492	8,730,034	17.1
Race/ethnicity			
White	2,644	24,508,125	10.8
Black	441	7,855,824	5.6
Other	322	7,263,537	4.4
Hispanic	348	7,794,360	4.5
Insurance			
Private	961	5,573,604	17.2
Medicare	196	270,844	72.4
Medicaid	2,040	9,473,651	21.5
Age ≥65 years	5,447	2,324,090	234.4
Gender			
Male	3,095	1,026,228	301.6
Female	2,352	1,297,862	181.2
Race/ethnicity			
White	4,814	1,991,267	241.8
Black	107	136,651	78.3
Other	177	161,583	109.5
Hispanic	41	34,589	118.5
Insurance			
Medicare	4,814	1,991,267	241.8
Medicaid	5,447	2,324,090	234.4

Source: Lewin analysis of Optum dNHI de-identified administrative claims data 2021-2024, Medicare SAF 5% 2022-2023, and Medicaid T-MSIS 2021-2022.

	Incident* Cases	Person years	Incidence per 100,000 Population Person years
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*Incidence ascertained by 24 months clean lookback without prior diagnosis of PD or AP.

B.2. Prodromal Characteristics

The prevalence of selected prodromal symptoms observed in the 12 months prior to diagnosis are shown in Exhibit 30. In the 12 months prior to diagnosis of PD or AP, the most common prodromal symptom observed by diagnosis code on a medical claim was gait disorder among privately insured and Medicare beneficiaries. Among Medicaid beneficiaries, mood disorder was the most prevalent, followed by major depressive disorder. Among those ages 18 to 64 with private insurance or Medicare, the next most common were those diagnoses related to mood or affect (major depressive disorder, mood disorder, and anxiety) and among those ages 65 and older the next most common diagnoses were major depressive disorder, anxiety, and constipation. Despite olfactory dysfunction being a strong marker for PD, only a handful of Medicare beneficiaries over age 65 had evidence of this diagnosis.

Exhibit 30. Prodromal Symptoms* Prior to Formal Diagnosis with Parkinson's Disease or Atypical Parkinsonism by Age Group and Insurance Type

	<65			≥65
	Private	Medicare	Medicaid	Medicare
N	2,033	295	1,822	7,195
Mild cognitive impairment	0.0%	1.4%	1.5%	4.1%
Major depressive disorder	6.0%	4.7%	18.1%	7.4%
Olfactory dysfunction, hyposmia	0.0%	0.00%	0.0%	0.0%
Orthostatic hypotension	0.0%	0.7%	1.5%	2.8%
Tremor disorders	0.0%	2.0%	6.8%	6.0%
Speech impairment	1.6%	1.7%	2.5%	2.5%
Gait disorders	6.7%	9.2%	12.8%	18.0%
Constipation	2.4%	2.7%	9.4%	7.7%
Mood disorder	6.5%	2.0%	31.1%	1.6%
Anxiety	9.3%	5.1%	18.1%	8.9%

Source: Lewin analysis of Optum dNHI administrative claims data 2021-2024, Medicare SAF 5% 2022-2023, and Transformed Medicaid Statistical Information System (T-MSIS) 2021-2022.

*Indicated by ≥1 medical claim with ICD-10 diagnosis in any position in the 12 months prior to formal diagnosis with PD or AP. ICD-10 diagnosis codes used for identification of prodromal symptoms can be found in Appendix C. Code Lists, Exhibit C 3.

B.3. Direct Medical Costs in the 12 Months Prior to Formal Diagnosis

We estimated the annual per capita medical costs in the 12 months prior to formal diagnosis with PD or AP by type of service (Exhibit 31). We compared the per capita medical costs in the 12 months prior to diagnosis with the average costs for the same age and insurance type with no PD or AP diagnosis. Relative to costs for the same age and insurance type with no diagnosis, costs were higher overall for PWPD/AP in the 12 months prior to formal diagnosis. Costs among privately insured aged 18-64 were 30% higher. As

noted in our discussion of direct medical costs attributable to PD and AP, Medicaid beneficiaries receiving these diagnoses were more likely to meet requirements for and receive disability benefit, which in part explains the difference in medical costs between the comparison group and those diagnosed.

Exhibit 31. Per Capita Direct Medical Costs* in the 12 Months Prior to Formal Diagnosis by Age and Insurance

	<65			≥65
	Private	Medicare	Medicaid	Medicare
N	2,033	295	1,822	7,195
Type of Service				
Non-acute institutional	\$128	\$10,444	\$5,290	\$8,163
Hospital inpatient	\$4,681	\$11,368	\$2,068	\$7,971
Hospital outpatient	\$5,469	\$5,160	\$501	\$4,277
Office visits/ ambulatory care	\$3,722	\$8,056	\$10,725	\$7,425
Durable medical equipment	\$32	\$667	\$121	\$461
Prescription medications	\$2,116	\$3,668	\$2,204	\$2,535
Total	\$16,147	\$39,363	\$20,910	\$30,832

Lewin analysis of Optum dNHI administrative claims 2022-2024, Medicare SAF 5% 2022-2023, and Transformed Medicaid Statistical Information System (T-MSIS) 2022.

*CPI adjusted to 2024 USD.

Costs were higher in the 12 months prior to formal diagnosis relative to the same age and insurance group (Exhibit 32). On average, among those who went on to be diagnosed with PD/AP costs were \$10,465 higher in the 12 months prior to diagnosis compared with those without PD/AP diagnosis. Costs among privately insured aged 18-64 were 30% higher. Among Medicare beneficiaries ages 18-64 and 65 years and older, costs were 60% and 50% higher for PWP/AP prior to diagnosis compared with those the same age without PD or AP diagnosis (Exhibit ES 8). Among Medicaid beneficiaries, costs were more than 5-fold greater for PWP/AP prior to diagnosis compared with those the same age without PD or AP diagnosis.

Exhibit 32. Per Capita Medical Costs* and Cost Ratios Prior to Formal Diagnosis Relative to Comparison Group

	<65			≥65
	Private	Medicare	Medicaid	Medicare
Prior to diagnosis with PD/AP	\$16,147	\$39,363	\$20,910	\$30,832
Comparison group without PD/AP	\$12,482	\$24,392	\$3,702	\$20,326
Excess	\$3,665	\$14,987	\$17,208	\$10,506
Cost Ratio^	1.3	1.6	5.6	1.5

Lewin analysis of Optum dNHI administrative claims 2022-2024, Medicare SAF 5% 2022-2023, and Transformed Medicaid Statistical Information System (T-MSIS) 2022.

*CPI adjusted to 2024 USD.

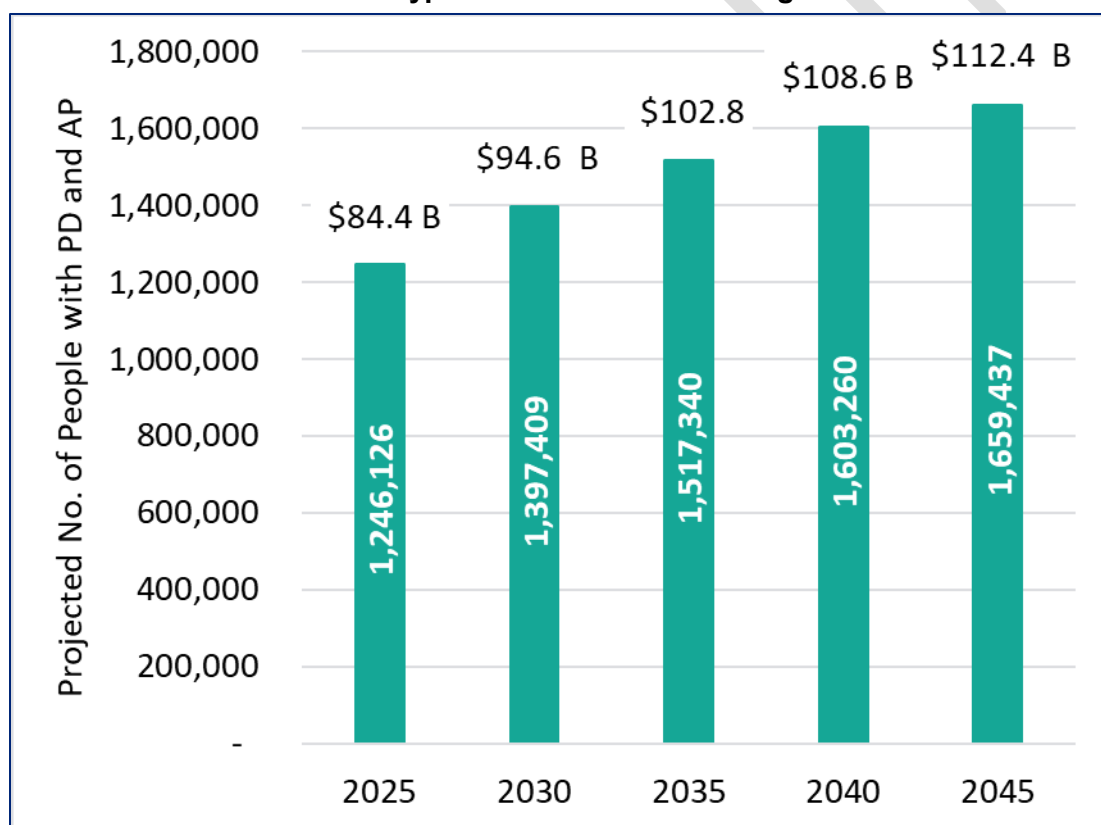
^Cost ratio for average per capita medical costs prior to diagnosis relative to same age group and insurance type with prevalent PD and AP.

C. Future Prevalence and Cost Projections

We estimated the size of the future PD and AP population in the U.S. and the estimated total economic burden in current dollars. According to our conservative approach that assumes the current incidence and mortality rates remain constant, the PD and AP prevalence is projected to increase from approximately 1.2 million PWPDP/AP in 2025 to 1.5 million in 2035 and then to approximately 1.7 million in 2045 (Exhibit 33). However, if we account for incidence in projecting prevalence, our estimate will largely increase.

Using the conservative approach, the corresponding total economic burden is projected to be \$84.4 billion in 2025 and then \$102.8 billion and \$112.4 billion in 2035 and 2045, respectively.

Exhibit 33. Projected Prevalence and Economic Burden* of Parkinson's Disease and Atypical Parkinsonism Through 2045



Source: Prevalence - Lewin analyses of 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projections for 2025-2045. Economic burden - Lewin analysis of PD and AP prevalence and economic burden in 2024 combined with Census population projections.
*in 2024 USD.

D. Care Partner Burden

We complement our estimates of current and future economic burden of PD and AP with information describing the care partner experience from our survey. Specifically, we describe the composition of the

care partner network, missed experiences and opportunities, and the impact of care responsibilities on the physical, emotional, and financial well-being of care partners.

D.1. Describe Care Partner Network

In total, almost 40% of PWP/AP received care from at least one unpaid care partner in 2024 (Exhibit 34). On average, PWP had 2.3 unpaid care partners. In total, 86% of unpaid primary care partners were identified as significant others, 13% were children, 4% were friends, 2% were siblings, and 3% were identified as other (data not shown).

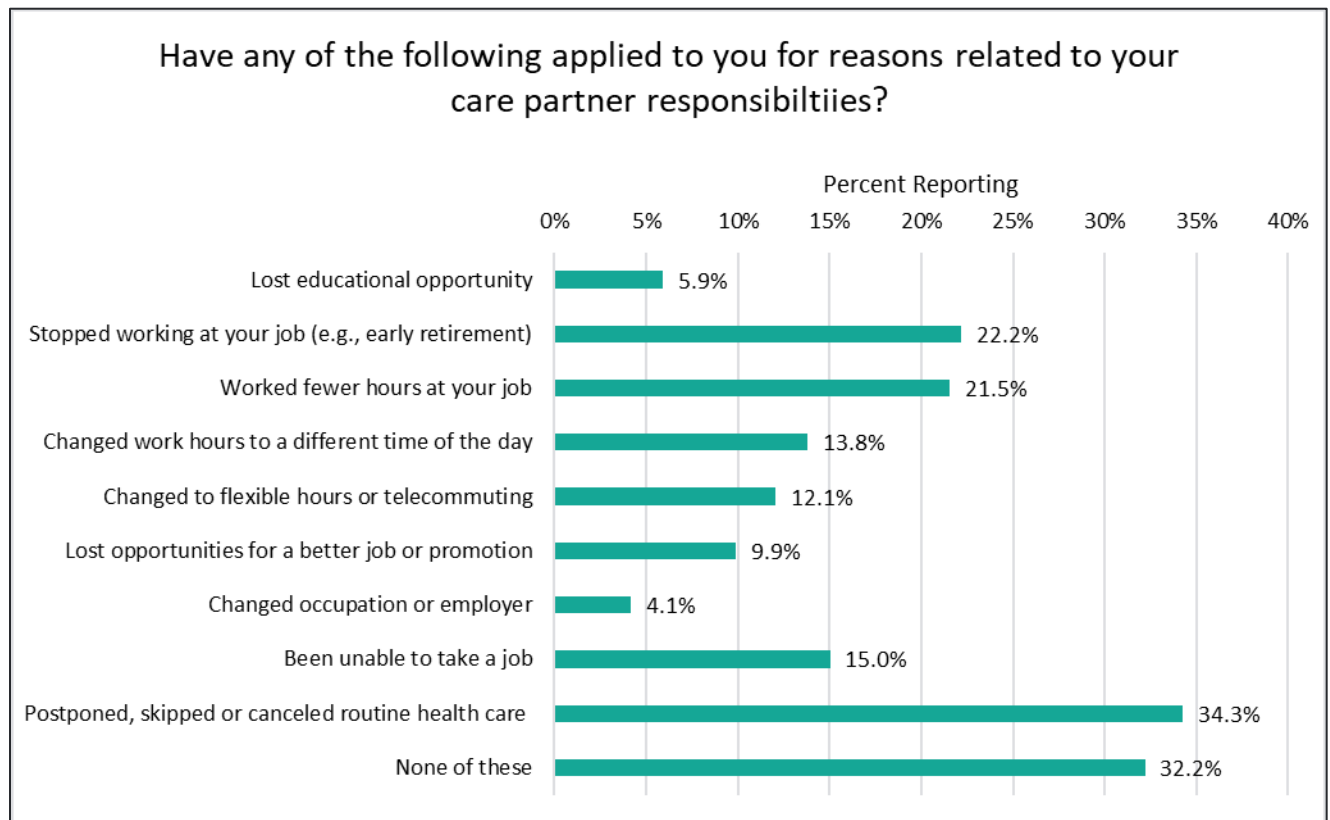
Exhibit 34. Percentage of Persons with Parkinson's or Atypical Parkinsonism who Received Unpaid Care from a Care Partner in the Past 12 Months

Gender and Age Group	Survey Respondents	Number Receiving Unpaid Care	Percent Receiving Unpaid Care	Average Number of Unpaid Care Partners
Males				
18-49 years	35	8	22.9%	1.5
50-64 years	440	134	30.5%	2.1
65-74 years	926	323	34.9%	1.5
≥75 years	866	391	45.2%	1.8
Females				
18-49 years	77	41	53.2%	5.5
50-64 years	557	220	39.5%	2.1
65-74 years	986	408	41.4%	1.8
≥75 years	696	292	42.0%	2.3
Overall	4,583	1,817	39.6%	2.3

Source: Lewin analysis of 2024 PD and Related Disorders Impact Survey.

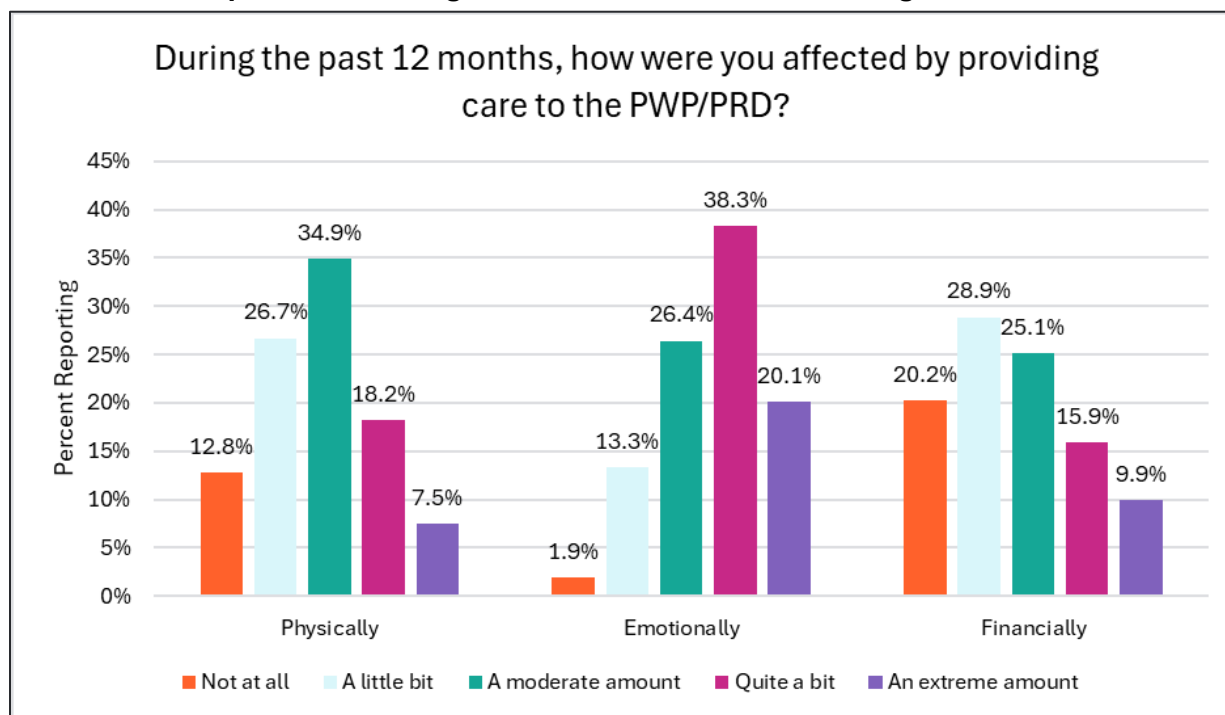
D.2. Care Partner Experience

We also asked care partners how care responsibilities impacted their lives in terms of education, employment opportunities, and self-care. While 32% of care partners reported that their care responsibilities did not result in any missed opportunities or self-care, over 20% retired or worked fewer hours at their job and 34% canceled or missed their own routine health care visits (Exhibit 35).

Exhibit 35. Impact of Care Partner Responsibilities

Source: Lewin analysis of 2024 PD and Related Disorders Impact Survey.

The 2024 PD and Related Disorders Impact survey captured responses from care partners about how the care responsibilities affected their well-being physically, emotionally, and financially (Exhibit 36). When asked how providing care affected them physically, approximately 35% said “a moderate amount” and over 25% said “quite a bit” to “an extreme amount” and almost 60% said providing care affected them emotionally “quite a bit” or “an extreme amount”.

Exhibit 36. Impact of Providing Care on Care Partner Well-Being in the Past 12 months

Source: Lewin analysis 2024 PD and Related Disorders Impact Survey.

IV. Discussion

Summary

This study updates previous estimates of prevalence and economic burden of Parkinson's disease and related disorders in the United States. Our previous report used ICD-9 diagnosis codes to identify PD and other neurodegenerative conditions (including PSP and CBD/S) but did not distinguish between PD and AP prevalence rates. This updated study relies on ICD-10 diagnosis codes which allow us to differentiate and include additional AP diagnoses. We estimated 1.2 million individuals, aged 18 years and older, in the U.S. to have PD or AP in 2024 (1.04 million in the previous report). The total economic burden 2024 PD and Related disorders, inclusive of atypical parkinsonism, in 2024 was \$82.2 billion, including \$23.8 billion in excess direct medical costs attributable to PD and AP and an additional \$26.2 billion in indirect costs and \$23.9 billion in non-medical and out-of-pocket medical expenses not covered by insurance. This study expands on previous economic burden estimates by expanding inclusion of atypical parkinsonism diagnoses and examining medical costs prior to formal diagnosis with PD or AP.

Another highlight of this study is the newly enhanced 2024 PD and Related Disorders Impact Survey. This survey included questions to collect information from PWP/PRD and their care partners on symptoms, workforce participation and productivity loss, and an array of non-medical costs included in the previous Social and Financial Impact of Parkinson's Disease Survey. In order to more fully capture how people living with PD and AP and their care partners are impacted by disease, we added new questions to capture more detail on non-medical costs, such as legal and financial planning, as well as care partner experience and well-being.

Parkinson's Disease Prevalence

Previous studies reported different estimates and projections of the national prevalence of PD, driven by the source of the data, age of the population studied, region, year of the study, and the method of analysis (Exhibit 37). Depending on the study objective and research question, the specific definition for identifying PD varies with some studies including some forms of AP and others strictly PD. For instance, several previous reports relied on ICD-9 diagnosis codes, specifically ICD-9 332, which includes secondary parkinsonism [15, 16, 5]. Marras et al used ICD-9 332 in combination with 333.0 (degenerative disease of basal ganglia) and 331.82 (dementia with Lewy bodies) as well as cohort study data that allowed capture of PD and AP diagnoses [14]. A more recent study by Pearson et al used ICD-10 G20.* in the primary or secondary position to identify PD in Medicare FFS claims data [13]. Using an approach consistent with our previous study, we estimate the size of the population with PD and AP in 2024 to be 1.21 million, 1.09 million of which have a diagnosis of PD which equates to a 5% increase in the size of the prevalent population since 2017.

Our study relied on nationally representative data sources to estimate the size of the population with PD and AP so that our estimate includes multiple insurance types (e.g., privately insured, Medicare and Medicaid beneficiaries, and other insurance types). Other studies relied on Medicare claims data to estimate prevalence, which may underestimate the size of the population by not including other insurance types [13, 14, 15]. For instance, the study by Pearson et al reported approximately 685,000 Medicare beneficiaries with PD in 2019 [13]. Willis et al also used Medicare claims data to calculate PD prevalence in 2005, overall and by age, gender, race, and region and estimated the mean prevalence as 1,588 per 100,000 Medicare beneficiaries over age 65 (PD prevalence rate = 1.59%) from 1995, 2000-2005 [15]. They also reported a steady increase of PD prevalence with age and higher prevalence among Black males and more concentration in the Midwest and Northeast regions. Other studies used national survey data to estimate prevalence [16, 17]. A study by Kowal et al. used national surveys of MEPS and National Nursing Home Survey (NNHS) and estimated approximately 630,000 individuals over age 65 with PD diagnosis (PD prevalence rate = 1.2%) in 2010 in the US and projected the PD prevalence to double by 2040 [16]. Our previous study estimated prevalence of 1.04 million in 2017 and projected prevalence in 2037 to exceed 1.6 million [5].

Exhibit 37. Comparison of the Current study with PD Prevalence Estimates in the Literature

U.S. Burden Study	Data Source(s)	Identification of PD	Year Estimated	Estimated Size of Prevalent Population
Current study	MCBS and MEPS	ICD-10 G20.*	2024	1,213,963
Pearson et al, 2023 [13]	Medicare FFS claims	ICD-10 G20.* in primary or secondary position	2019	808,107
Yang et al, 2020 [5]	MCBS and MEPS	ICD-9 332.*	2017	1,037,211
Marras et al, 2018 [14]	Administrative data, Medicare FFS	ICD-9 332.*, 332.1, 333.0, 331.82 with chart review PD, parkinsonism, tremor, PSP, MSA, non-specific	2010	680,000

U.S. Burden Study	Data Source(s)	Identification of PD	Year Estimated	Estimated Size of Prevalent Population
	Rochester Epidemiology Project Registry data	neurodegenerative diseases in medical record ICD-9 332 or ICD-10 G20.*		
Kowal et al, 2010 [16]	MEPS and NNHS	ICD-9 332.*	2010	630,000
O'Brien et al, 2009 [17]	NHIS and NAMCS	ICD-9 332.0	2007	500,000
Willis et al, 2010 [15]	Medicare FFS claims	ICD-9 332, 332.0 (excluded 333.0)	2005	450,000
Huse et al, 2006 [18]	MarketScan Research Database	ICD-9 332.0	2002	645,000

MCBS Medicare Current Beneficiary Survey; MEPS Medical Expenditure Panel Survey; FFS Fee For Service; NNHS National Nursing Home Survey; NHIS National Health Interview Survey; NAMCS National Ambulatory Medical Care Survey.

*Indicates inclusion of all codes that begin with these digits.

Using multiple data sources (including healthcare administrative databases, registry databases, and Medicare claims data) from diverse regions in North America, Marras et al estimated 680,000 PWPDs (PD prevalence rate = 0.57%) in the US aged ≥ 45 years in 2010 and that that number would rise to approximately 930,000 in 2020 and 1,238,000 in 2030 [14]. A recent study used data on self-reported PD from the Fox Insight (FI) study and data from the epidemiologic literature, the U.S. Census Bureau, Medicare, and the National Health and Aging Trends Study to simulate a virtual census of the PD population and logistic regression to compare the PD census to the FI cohort [7]. The study estimated 849,488 PWPDP in the U.S. in 2019 (based on 22,465 PWPDP in the FI cohort) and found that PWPDP who did not participate in the FI study were more likely to be older, female, non-White, and to have more severe PD and lower levels of education. These findings suggested that the underestimation of the PD population is related to their underrepresentation and that methods as inverse probability weighting are needed to generate reliable national estimates. To mitigate potential underestimation, our study uses more recent data and nationally representative data to update the estimated size of the population with PD and AP in 2024 based on age-gender-insurance strata and weighted estimates of the prevalent population.

Furthermore, our PD prevalence estimate of 1.09 million (PD prevalence rate = 0.41% overall and 1.33% for those aged 65 years and older) in 2024 reflects the increased death counts of patients with PD during the COVID-19 pandemic era [35, 33, 34]. Previous research found that age-adjusted PD-related mortality rates increased since 1999, peaking at 119.6 per 100,000 in 2020 exceeding projected mortality [33]. In addition, there is evidence that COVID-19-related mortality among those with severe neurologic conditions was nearly 3-fold higher (24.7%, estimated 25,964 excess deaths) compared with all-cause mortality rates during COVID-19 (7.9%) and pre-COVID-19 (6.8%) [34].

Atypical Parkinsonism Prevalence

Little research has been conducted on AP prevalence, while several studies estimated the prevalence of individual conditions (e.g., PSP, MSA). A review of studies conducted in different countries reported the prevalence of PSP or MSA as less than 10 per 100,000 (and below 5 per 100,000 for CBS) [36]. Our estimated prevalence of AP (DLB, MSA, PSP, CBS, Vascular parkinsonism, and parkinsonism not otherwise specified) is 46 per 100,000 (121,547 AP patients). Few studies have reported AP prevalence in the U.S. Our study takes advantage of the enhanced specificity afforded by ICD-10 diagnosis codes that allow us to estimate prevalence rates and per capita costs for people living with a range of AP diagnoses. Our estimates of individual AP conditions indicate higher prevalence than what has been previously reported. For example, compared to previously reported PSP prevalence of 2.95 per 100,000 in 2016, we estimated 4.72 per 100,000 PSP prevalence in 2024 (Appendix F. Landscape Formatted Exhibits, Exhibit F 1) [19].

Direct Medical Costs for Payers and Patients

A number of studies have reported the burden of PD in terms of direct medical and indirect costs (Exhibit 38). We estimated that PD/AP is associated with an excess medical cost of \$23.8 billion in 2024, slightly lower than our previous PD/AP estimate due to factors that we will discuss below. Most of the medical cost of PD or AP is borne by populations eligible for Medicare coverage (89%), 6% by those with private insurance, 4% by those covered by Medicaid, and <1% by those in the other group (including other insured and uninsured). In total, excess direct medical costs account for 29% of the total economic burden, 93% of which is paid by Medicare and Medicaid.

Exhibit 38. Comparison of the Current Study with PD Burden Estimates in the Literature

U.S. Burden Study	Year Estimated	Estimated Size of Prevalent PD Population	Direct Cost	Indirect and Non-Medical Costs
Current study	2024	1,213,963* in 2024	\$23.8 billion 2024 USD	\$58.4 billion in 2024 USD
Yang et al, 2020 [5] [5]	2017	1,037,211* in 2017	\$25.4 billion 2017 USD	\$26.5 Billion 2017 USD
Kowal et al, 2010 [16] [16]	2010	630,000* in 2010	\$14 billion in 2010 USD	\$6.4 Billion in 2010 USD
O'Brien et al, 2009 [17] [17]	2007	500,000 in 2007	\$6.2 billion in 2007 USD	\$4.6 billion in 2007 USD
Huse et al, 2006 [18] [18]	2002	645,000 in 2002	\$6.7 billion in 2002 USD	\$16.3 billion in 2002 USD

*Includes AP diagnoses as indicated in Exhibit 37.

While total excess cost for hospital inpatient was the largest cost driver among the privately insured persons with PD or AP (37% of the \$1.4 billion for the privately insured), non-acute institutional care was the largest among Medicare eligible beneficiaries with PD or AP (45% of the \$21.3 billion for Medicare eligible persons with PD or AP) and Medicaid eligible beneficiaries (43% of the total \$0.9 billion in excess costs for Medicaid); and hospital inpatient represents the largest share of PD/AP cost among the Other group (37% of the \$0.2 billion). Per capita excess cost was \$13,181 and \$38,942 for the privately insured (<65) and the Medicaid group (<65) of PD or AP, respectively; and \$20,117 for the Medicare eligible population with PD or AP (including those <65 due to disability and anyone ≥65 years of age). Our estimated per capita excess medical costs attributable to PD or AP was higher for Medicaid beneficiaries compared with other insurance

types, primarily driven by non-acute institutional care and office visits (\$16,646 and \$14,822, respectively (previously shown in Exhibit 15). This is primarily due the comparison group for Medicaid beneficiaries without PD or AP having very low per capita medical costs as shown in Appendix F. Exhibit F 2 .

Due to the nature of PD and AP, cost of long-term care has been a concern in the PD and AP communities. In this study we defined long-term care more broadly by including cost of non-acute and post-acute care, skilled nursing facilities, 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 or AP in non-acute institutional care to be \$10.0 billion. Consistent with our previous study, the total costs for non-acute institutional care were the highest compared to other service types, driving the direct medical costs among the Medicare beneficiaries with PD and indicating the high demand of long-term care among older patients with PD. A recent report by the National Alliance for Caregiving found that 9% of patients with PD lived in nursing or long-term care facility [21].

While our 2024 total economic burden of PD or AP in this study is higher than the PD/AP economic burden in 2017 reported in our previous study (\$82.2 billion versus \$51.9 billion, respectively), our estimate of excess direct medical costs for PD/AP is slightly lower than our previous estimates (\$23.8 billion versus \$25.4 billion, respectively). Indeed, total medical costs for those with diagnoses of PD and AP increased since our previous report, however, the magnitude of increase for the comparison group without PD or AP was greater, thus narrowing the attributable difference. A number of other factors contribute to this slight reduction in our current estimates of attributable direct medical costs. First, the current PD prevalence increased among the younger age group (<65), which is in line with the occurrence of young-onset Parkinson's disease [20]. This younger group is likely healthier than the older group (has lower number of comorbidities or none) and therefore incurred lower per capita costs (both privately insured and Medicare beneficiaries). Second, higher mortality among those aged 65 years and older during the COVID-19 pandemic might have caused a reduction in the direct medical costs; the highest mortality rates under COVID-19 were seen in groups with comorbid conditions associated with advanced PD/AP [37].

Since direct medical costs generally increase with age and disease progression, any relative spike in mortality during the years immediately preceding this estimate could disproportionately impact the average per capita cost for PWP/AP. Third, there were considerable increases in comparison group per capita costs for both private and Medicare and for all age groups. This could be related to diseases with higher expenses than PD in the comparison group. For example, the comparison group in our Medicare analysis included patients with cancer (e.g., cytopenia, lymphoma) and genetic diseases (e.g., Gaucher disease, Pompe disease, Hemophilia, Hereditary factor IX deficiency, Hurler-Scheie syndrome, Fabry disease) that incurred substantial costs across types of service (data not shown). A previous study estimated approximately \$193 billion total excess medical costs due to rare diseases in the Medicare population in 2019 [38]. In addition to these costly diseases, the high costs in the comparison group could be related to newer expensive treatments used by patients in this group (other than PD patients); these treatments were not available for patients during our previous study. For example, aducanumab (Aduhelm), used to treat Alzheimer's disease, was approved by the FDA in 2021 and had a \$28,000 (initially \$56,000) annual cost [39]. Other examples include gene therapies, treatments for cancer and rare diseases as well as organ transplants and the new diabetes therapy. Gene therapies include those used for hemophilia B (e.g., etranacogene dezaparvovec-drlb (Hemgenix), approved by the FDA in 2023, and fidanacogene elaparvovec-dzkt (Beqvez), approved by the FDA in 2024 [discontinued in 2025]; each had a list price of \$3.5 million or a single-dose treatment [40, 41, 42, 43]. Several expensive cancer treatments were recently approved by the FDA,

including tebentafusp-tebn (Kimmtrak), approved in 2022 for metastatic uveal melanoma and had a list price of about \$1 million per year; ciltacabtagene autoleucel (Carvykti), approved in 2024 for multiple myeloma and had a list price of approximately \$0.5 million for a single-dose treatment [44, 45, 46]. The newer diabetes and obesity therapy, glucagon-like peptide-1 (GLP-1) agonists, has seen significant growth in the past five years that peaked in 2022 and 2023, accounting for 16% of prescriptions and driving the combined diabetes and obesity spending growth to \$13 billion in 2023 [47]. Fourth, our analysis of more recent MCBS data estimated per capita prescription medication costs to be lower than what was reported in the previous study, which may reflect limitations to using these data as they rely on self-report and have been shown to underestimate costs in some cases [48]; however, we also asked about out-of-pocket prescription drug costs in the 2024 PD and Related Disorders Impact Survey and those self-reported costs were even lower (data not shown).

Indirect Costs

To assess indirect costs, we estimated premature death, net present value of future earnings, labor market employment/related earnings loss, labor market productivity loss, and social productivity. We estimated total indirect and non-medical costs of PD and AP as \$58.4 billion in 2024. Per capita indirect costs for PWP/DP/AP and care partner were \$48,101, which is greater than per capita indirect costs for other conditions such as diabetes (per capita indirect cost for diabetes was estimated to be around \$4,500 in 2022 USD), indicating the huge burden of PD/AP for patients and their care partners [12]. We estimated 18,096 premature deaths among the PWP/DP/AP associated with net present value of \$3.1 billion lost earnings in 2024 (exceeding the estimated lost earnings of \$2.5 billion (2017 USD) in our previous report). The number of premature deaths due to PD or AP is lower than the previous study (18,069 in the current study compared to 23,393 in the previous study) [5]. For each gender-age group, we estimated slightly higher mortality rates compared with the previous study, however, because the age distribution of the population with PD has shifted, a larger proportion are younger relative to the previous study, and the mortality rates for those under age 50 are relatively low, thus contributing fewer deaths attributable to PD or AP. This lower estimate of PD/AP premature deaths due to PD/AP could be related to the high mortality among individuals with advanced PD/AP progression during the COVID-19 pandemic that resulted in lower premature deaths during the study period. While there are no other sources to confirm this estimate, we believe that our estimate is accurate as we used multiple data sources and adjusted for the low death rate for PWP/DP in CDC WONDER.

For labor market employment/related earnings loss, our results supported previous research that reported 11% of PD care partners gave up working due to care responsibilities [21]. We found that among PWP/DP/AP and care partners who reported that they were no longer working, 12% of patients and 13% of care partners indicated that the disease and care responsibilities, respectively, played a role in their decision. Further, we estimated \$6.7 billion of early retirement-earnings loss among PWP/DP/AP and \$1.7 billion among care partners; the total estimate exceeded our previously reported one.

Among those still employed, we estimated approximately \$6 billion for PWP/DP/AP and a similar amount for care partners as labor market productivity loss due to PD or AP related absenteeism in 2024; triple the amount we previously reported [5]. Productivity loss was higher among male PWP/DP/AP and female care partners compared to their counterparts. We found the total cost of absenteeism to be three times greater for male than female PWP/DP/AP ages 50 to 64 years old, despite they missed the same number of days work per month; aligning with the gender pay gap [49]. Consistent with the current research, the

proportion of female care partners was higher than that of male care partners, and therefore, the total of cost of absenteeism was higher among the female relative to the male care partners [21]. Our findings on presenteeism were consistent with those on absenteeism. Our unique survey questions on social activities concluded that a diagnosis of PD or AP led to a 50-70% reduction in an individual's ability to participate in voluntary activities. This reduction was associated with an estimated total annual social productivity loss of approximately \$1 billion for PWPD/AP and \$0.3 billion for care partners.

Non-Medical Costs and Out-of-Pocket Expenses Not Covered by Insurance

Previous studies included fewer non-medical cost components than the current study. Our previous study captured non-medical costs for PWPD/AP related to home modifications, vehicle purchases, and increased transportation costs that accounted for approximately \$7.6 billion in 2017 USD [5]. The current study estimated the total cost of non-medical costs included in the previous study to be \$12.4 billion plus an additional \$11.5 billion in non-medical costs and medical-related out-of-pocket expenses not covered by insurance added to the enhanced 2024 PD and Related Disorders Impact Survey. These added cost components reflect the considerable burden for PWPD/AP and their families.

Future projections

Our projected prevalence for 2025-2045, assuming current incidence and mortality rates remain constant, shows an increase in counts of PWPD/AP and economic burden over years. Our projected prevalence counts are 1.2, 1.5, and 1.7 million patients with PD or AP in 2025, 2035, and 2045, respectively. Available prevalence studies started with a lower PD prevalence estimate than ours and therefore future projections in these studies seem also lower. For example, Rossi et al used both historical and projected U.S. population data from 1990 to 2040 and predicted approximately 770,000 PD cases by 2040, accounting for both aging and declining smoking prevalence [50]. Using Global Burden of Disease Study 2021 (using 1990-2021 data), a recent study projected 893,000 PWP in the US in 2050 [51].

Our projected economic burden (2024 USD) ranges between \$84.4 billion in 2025 and \$112.4 billion in 2045. Our previous study predicted an increase (2017 USD) from \$51.9 billion in 2017 to \$67.1 and \$79.1 billion in 2027 and 2037, respectively). Our 2024 actual economic burden exceeds the previously projected 2027 estimate due to the increased indirect and non-medical medical costs reported by PWPD/AP in the survey [5].

Incidence of Parkinsons and Atypical Parkinsonism

Recent reports of PD incidence are summarized in Exhibit 39. Incidence rates for U.S. adults have ranges from 21 to 212 per 100,000, depending on the specific age group, data used, and method of ascertaining incidence, summarized in Exhibit 39 [52, 6, 53]. For instance, some studies rely on Medicare claims data restricting their estimate to those ages 65 and older [6] and other use data that facilitates broader generalization [53]. Using more recent data for multiple payers, we estimated PD incidence of 48 per 100,000 for the U.S. adult population, which is higher than other studies reporting incidence for all ages [54, 53]. Consistent with other reports, we observe marked increase in incidence with age. We estimate PD incidence for the population age 65 and older at 234 per 100,000, which is higher than the 212 per 100,000 Willis et al that also used Medicare claims data to ascertain incidence in 2012 [6]. Our higher incidence rate could be due to increased awareness and recognition of symptoms and disease or greater sensitivity due to changes in diagnostic coding and should be replicated with other data. Additionally, it should be noted that we relied on administrative claims data to ascertain incidence, which may be prone to misclassification of disease status and overestimate the true incidence. While our definitions for ascertainment of incident

disease were very specific, available data limited our length of observation prior to diagnosis to 24 months, which may have misclassified some prevalent cases as incident, thus potentially inflating our incidence rates.

Exhibit 39. Parkinson's Disease Incidence from the Literature

Study	Population	Data Source(s)	Identification of PD	Age Group	Parkinson's Incidence per 100,000
Current study	United states, in 2024	Optum claims for privately insured ^{^Y} US Medicaid (2022) ^{^Y} US Medicare (2022-2023) ^{^Y}	ICD-10 G20.*, G21.4, G23.1, G23.2, G31.85	All ages <65 ≥65	47.7 21.5 234.4
Li et al, 2025 [52]	United States, all ages in 2021	Multiple data sources	ICD-10 G20.*, G21.*, G22.*	All ages	26.2
Willis et al, 2022 [6]	United States and Canada, over 65 in 2012	Kaiser Permanente Northern California (2012) ^{^Y} Rochester Epidemiology Project ^Y US Medicare (2012) ^Y Ontario health administrative database ^{Y^A}	Medical record review ICD-9 332.* or ICD-10 G20.*	≥65 ≥65 ≥65 ≥65	125 108 212 185
Savica et al, 2017 [53]	Rochester, MN all ages in 2005	Rochester Epidemiology Project (1976-2005) ^Y medical records with clinical confirmation	Medical record review	All ages 0-39 40-59 60-69 70-79 80-99	17.2 0.1 9.2 55.1 119.2 133.9

Ascertainment of Incidence:

*Includes all diagnosis codes that begin with these digits.

[^]2 OP or 1 IP diagnosis made by physician or advanced practice provider.

^YRequired 24 months clean lookback without prior diagnosis.

For the population under 65, most studies report incidence for the entire population or for ages 45 and over. A study by Savica et al reported age-group incidence for PD for ages 40-59 to be 9 per 100,000, which is similar to our estimate for the 18-64 age group [53]. For the population aged 18 to 64, we estimated PD+AP incidence to be 22 per 100,000. Both PD and AP are relatively rare in the younger age groups and may be underdiagnosed in this group.

Few studies have reported incidence of atypical parkinsonism broadly, while a few studies reported incidence of specific AP diagnoses, including dementia with Lewy Bodies, PSP, CBS, and early onset parkinsonism [55, 56, 57], however, there is generally a dearth of evidence on incidence of atypical parkinsonism. Our study is among the first to estimate incidence of a wide range of AP diagnoses using multiple data sources.

Costs Prior to Diagnosis

Many early symptoms of PD and AP are non-specific, which may result in avoidable delays in diagnosis. For instance, in the present study we observed depression, anxiety, and constipation to be relatively common in the 12 months prior to formal diagnosis with PD or AP using administrative claims data, which

may actually underestimate the prevalence of these symptoms as it only captures these when a patient seeks care. Interestingly, in many cases we observed slightly higher prevalence of these symptoms among those who went on to receive an AP diagnosis compared to the same age-gender-insurance sample who went on to receive a PD diagnosis. Delays in diagnosis can potentially lead to unnecessary testing and treatment and be costly for patients and the health care system. However, little is known about medical costs in the period prior to diagnosis with PD or AP. We estimated annual per capita costs in the 12 months prior to formal diagnosis with PD or AP by age group and insurance type. We observed considerably higher costs for PWP/DP/AP in the 12 months prior to diagnosis relative to those who did not go on to receive a PD or AP diagnosis. These higher costs may reflect patients seeking care and being treated for prodromal symptoms. Because many PD/AP prodromal symptoms lack specificity, the increased health care utilization relative to those who don't go on to receive a diagnosis, may be an indicator of a patient's diagnostic odyssey as they seek diagnosis.

Care Partner Experience

One of the most important updates to our current study was the inclusion of new questions in the 2024 PD and Related Disorders Impact Survey to capture the burden of unpaid care partners. We found that nearly 40% of PWP/DP/AP received care from an unpaid care partner in 2024. Over 20% of care partners retired or worked fewer hours at their job and 34% canceled or missed their own routine health care visits due to care responsibilities. Providing care affected care partners quite a bit or an extreme amount physically (51% of respondents), emotionally (49%), and financially (43%). Similar to previous research, these findings indicate the high burden and distress experienced by care partners [21].

While other conditions with greater prevalence or higher per capita costs may be related to higher economic burden, it can be argued that the care partner burden for PWP/DP/AP is greater. The National Alliance for Caregiving reported that care partners for PWP/DP/AP are tasked with a range of needs including emotional support, assistance with activities of daily living and hygiene, management of psychiatric symptoms and cognitive decline, navigating the health care system, and physical support to address motor symptoms and prevent falls with more PWP/DP/AP care partners reporting high burden of care compared with non-PD care partners [21]. In their report, "Caregiving in the U.S. 2020," the National Alliance for Caregiving and the American Association for Retired Persons, a combined 23% of care partners reported the care recipient's primary problem as mobility issues (12%) or dementia (11%), far greater than the proportions with cancer (6%), stroke (5%), or diabetes (3%) all of which are conditions with greater economic burden [58]. Among respondents to our 2024 PD and Related Disorders Impact Survey, unpaid care partners, on average, provide more than 8 hours of care per day, more than half of whom spent more than 40 hours per week providing care (data not shown). The complexity of care needs for PWP/DP/AP results in considerable burden for care partners.

Study Limitations

This comprehensive study of prevalence and economic burden of PD or AP also has several limitations. First, the potential omission of undiagnosed and misdiagnosed PD patients, which may also result in underestimating the costs attributable to PD [59, 60]. Early PD symptoms are sometimes considered 'normal aging,' leading to undiagnosed PD. In this study, we focused on diagnosed PD as it allows for using a pre-specified definition and has higher economic burden. Second, this study used private insurance claims to impute cost for the other (non-private, non-Medicare, and non-Medicaid covered PD population) group by age and gender; as such, our estimate may under- or over-estimate the true direct medical costs in this population, but overall the other insured population only accounts for 2% of the population PWP/DP/AP fall

into the other insurance group thus variation at the individual level would have minimal impact on our economic burden estimates. Third, 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 were 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 have small sample sizes. Fourth, Medicare SAF 5% only includes Medicare FFS beneficiaries, but not the Medicare Advantage enrollees. Enrollment in Medicare Advantage, the private plan alternative to traditional Medicare FFS, has increased steadily over the past two decades, with more than half of Medicare eligible beneficiaries were enrolled in a private plan in 2023 [61, 62, 63].

Fifth, some of AP diagnoses had small sample sizes in claims data; yet one of the strengths of this study is estimating AP prevalence and economic burden in addition to PD estimates as, to our knowledge, this is the first study to provide such estimates. Previous research has established that reliance on ICD codes to identify patients in claims data could lead to misclassification and/or underestimation of the cost of conditions such as AP [64]. To address this limitation, we take advantage of the increased specificity afforded by ICD-10 diagnosis codes using claims data from Medicare, Medicaid, and commercial insurance to capture additional patients and provide a more accurate estimate of the economic burden of AP [64, 55, 22]. Furthermore, we used claims data with MCBS to capture all costs associated with AP. Misclassification of disease status may be particularly problematic for ascertainment of incident disease. We employed specific definitions for identification of incident disease; however, available data limited our length of observation prior to diagnosis to 24 months. A validation study using Medicare claims data to ascertain incidence of 12 acute and chronic medical conditions, found observation prior to diagnosis shorter than 36 months led to increased false positives and inflated incidence rates [65]. Our incidence rates estimated from administrative claims data may overestimate the true incidence, thus in order to avoid overestimation in our future projections, we assumed no change in incidence rates based on the literature.

Sixth, our 2024 PD and Related Disorders Impact Survey was non-randomized, and the respondents represented a convenient sample from participants in the Fox Insight study and engaged by PD/AP patient organizations (The Michael J. Fox Foundation for Parkinson's Research, Parkinson's Foundation, Cure PSP, and American Parkinson Disease Association) and therefore the sample may not be representative of all the PD and AP population in the U.S. However, as these organizations represent the largest PD and AP patient and research organizations in the nation, the results might still be generalizable at the national level. Due to lack of existing sampling frame appropriate for surveying people living with PD and AP, we used a convenience sample for our survey. To mitigate potential bias resulting from our survey sample, we weighted survey responses to represent the U.S. population with PD and AP in 2024 across age- and gender-specific strata. In addition, the large sample size of the final responses to our survey, the diversity in the sample, and the weighting method used helped to mitigate the potential bias of non-response and non-representativeness. Seventh, as with any study that obtains data from a survey, the collected self-reported data were subject to recall bias and might have contributed to finding non-medical costs higher than those in the previous report. Eighth, some indirect costs reported by the survey respondents might have related to aging in general and not specifically PD or AP related, despite our clear survey questions. Ninth, some of the respondents to the survey were excluded from the analysis because they lived outside the U.S. (as this survey aimed to estimate the national economic burden) or reported a non-binary gender (because we had to supplement the survey data with census data such as earnings that are only reported for males and females).

Finally, there is a potential margin of error in our extrapolations and projections; however, using methods consistent with our previous study allows for valid comparison.

Conclusion

By including AP diagnoses, this study provides a comprehensive picture of the burden of PD and atypical Parkinsonism in the U. S. While excess direct medical costs attributable to PD and related neurodegenerative conditions have remained relatively stable since 2019 due primarily to increases in costs in the comparison group, our comprehensive approach identified significantly higher indirect medical costs and non-medical costs. Our analysis of indirect medical costs underscores the increasing load borne by PWPD/AP and their care partners in terms of workforce participation, earnings loss, and productivity loss. Further, we captured previously unreported categories of non-medical costs borne by households managing PD and AP, such as motor vehicle modifications and paid household help. These indirect medical and non-medical costs, in combination with the direct medical costs attributable to PD and AP represent an area ripe for interventions to alleviate symptoms and delay disease progression that forces PWPD/AP and their care partners to leave the workforce. Our examination of prodromal features and costs in the 12 months prior to formal diagnosis with PD or AP highlight the symptom burden for PWPD/AP. Future research should investigate the patient journey, as in clinical practice PWPD/AP may experience new or additional diagnoses.

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Appendix A. Supplemental Results

Parkinson's Disease Results

Prevalence of Parkinson's Disease

Exhibit A 1. Parkinson's Disease Prevalence by Population Characteristics

	No. of Persons Estimated to Have PD	Population	Prevalence
Age			
18-49	51,719	141,792,556	0.04%
50-64	222,591	61,660,017	0.36%
65-74	340,161	35,223,309	0.97%
≥75	478,036	26,298,663	1.82%
Gender			
Male	676,162	130,227,394	0.52%
Female	416,344	134,747,151	0.31%
Race/Ethnicity			
NH White	822,137	161,154,757	0.51%
NH Black	120,194	31,955,514	0.38%
Other	57,020	24,560,303	0.23%
Hispanic	93,156	47,303,971	0.20%
Insurance			
Private	99,423	138,862,094	0.07%
Medicare	945,452	73,280,221	1.29%
Medicaid	22,821	28,432,466	0.08%
Other insurance*	24,810	24,399,765	0.10%
Overall	1,092,506	264,974,545	0.41%

Source: Lewin analyses of 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2024.

*Other insurance includes other insurance not listed above such as Indian Health Services, military, and uninsured.

Direct Medical Costs

Exhibit A 2. Direct Medical Cost of Parkinson's Disease by Age and Gender, 2024

	Total Excess Medical Cost*^		Mean Excess Cost Attributable to PD (\$)
	Excess Cost (in Million \$)	Percentage of Total	
Males			
18-49 years	\$92	0.4%	\$2,734
50-64 years	\$3,275	15.5%	\$22,791
65-74 years	\$4,834	22.8%	\$19,986
≥75 years	\$4,502	21.2%	\$17,523
Females			
18-49 years	\$541	2.6%	\$29,948
50-64 years	\$1,515	7.1%	\$19,202

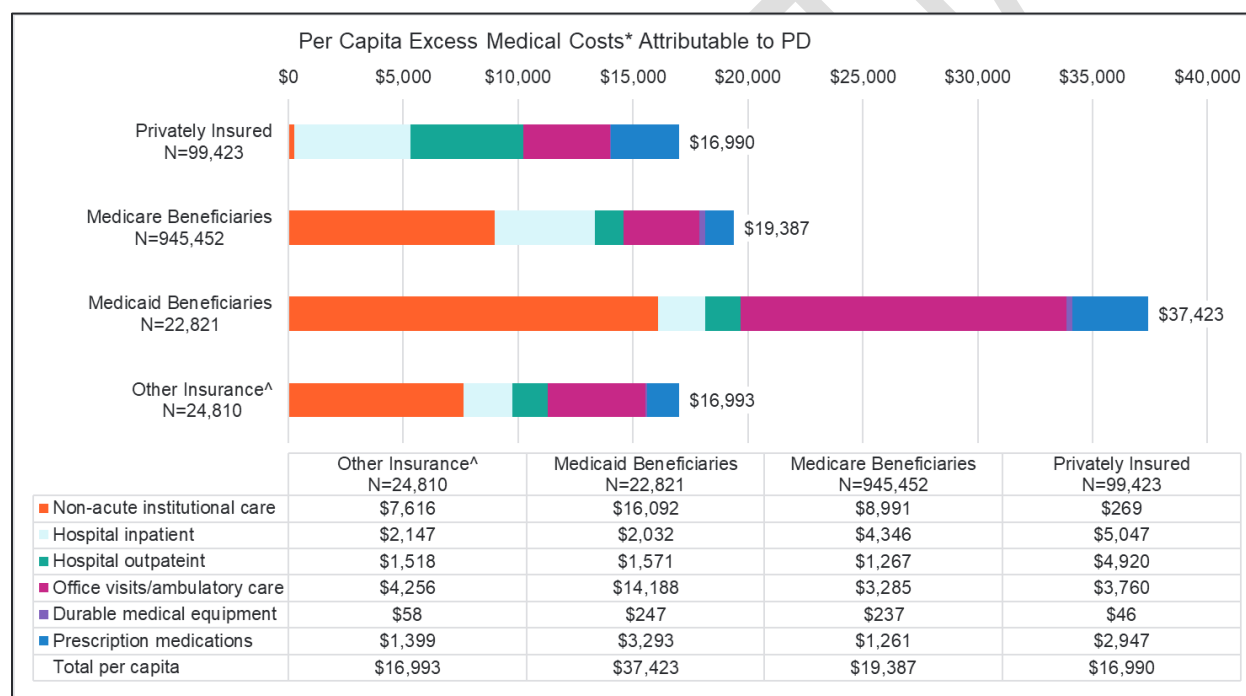
	Total Excess Medical Cost*^		Mean Excess Cost Attributable to PD (\$)
	Excess Cost (in Million \$)	Percentage of Total	
65-74 years	\$1,676	7.9%	\$17,050
≥75 years	\$4,757	22.3%	\$21,516
Overall	\$21,192		\$18,844

Source: Lewin analyses of PD and AP prevalence using 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2024; combined with direct medical cost estimates using 2024 Optum claims, 2023 Medicare Standard Analytical File 5% sample claims, and 2022 Medicare Current Beneficiary Survey (MCBS).

*CPI adjusted to 2024 USD.

^May not sum to Overall row due to rounding.

Exhibit A 3. Per Capita Direct Medical Cost* Attributable to Parkinson's Disease by Types of Service



*CPI adjusted to 2024 USD.

^Other insurance includes other insurance not listed above such as Indian Health Services, military, and uninsured.

Exhibit A 4. Total Direct Medical Cost* Attributable to Parkinson's Disease by Types of Service and Insurance

Total Excess Cost Attributable to PD (in millions)^	Private	Medicare	Medicaid	Other Insurance ^y
Type of Service				
Non-acute institutional care	\$27	\$8,500	\$399	\$19
Hospital inpatient	\$502	\$4,109	\$50	\$358
Hospital outpatient	\$489	\$1,198	\$39	\$349
Office visits/ambulatory care	\$374	\$3,106	\$352	\$267
Durable medical equipment	\$5	\$224	\$6	\$3
Prescription medications	\$293	\$1,192	\$82	\$209
Overall	\$1,689	\$18,329	\$928	\$1,206

Source: Lewin analyses of PD and AP prevalence using 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2024; combined with direct medical cost estimates using 2023 Medicare Standard Analytical File 5% sample claims, and 2022 Medicare Current Beneficiary Survey (MCBS).

*CPI adjusted to 2024 USD.

^May not sum to Overall row due to rounding.

^yOther insurance includes Indian Health Services, military, and uninsured

Indirect Costs

Exhibit A 5. Estimated Number of Premature Deaths Associated with Parkinson's Disease in 2024

	PD Death Rate	Non-PD Death Rate	Difference in Rates (PD - non-PD)	Estimated Number of Premature Deaths for PD
Males				
18-49 years	0.7%	0.3%	0.5%	165
50-64 years	2.4%	1.0%	1.5%	2,253
65-74 years	6.8%	2.6%	4.3%	8,364
Females				
18-49 years	1.1%	0.1%	1.0%	186
50-64 years	3.3%	0.6%	2.7%	2,122
65-74 years	5.9%	1.7%	4.2%	3,314

Source: Lewin analyses of 2022-2023 Medicare 5% sample claims data, and CDC WONDER 2022-2023 data.

Exhibit A 6. Estimated Net Present Value of 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 \$)^
Males			
18-49 years	165	\$1,195,551	\$198
50-64 years	2,253	\$428,159	\$965

	Estimated Number of Premature Deaths	Estimated Present Value of Future Earnings/Death (\$*)	Estimated NPV (in Million \$)^
65-74 years	8,364	\$69,940	\$585
Females			
18-49 years	186	\$1,020,494	\$190
50-64 years	2,133	\$353,358	\$754
65-74 years	3,314	\$49,481	\$164
Overall	16,415	\$173,923	\$2,855

Source: Lewin analyses of 2022-2023 CDC Wonder and 2023 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.

*CPI adjusted to 2024 USD.

^May not sum to Overall row due to rounding.

Exhibit A 7. Estimated Labor Market Earnings Loss due to Parkinson's Disease Related Unemployment

	Percentage Retired and Stopped Working due to PD	Total Earnings Loss (in Million \$)*
Males		
18-49 years	13%	\$261
50-64 years	24%	\$2,097
65-74 years	21%	\$2,241
Females		
18-49 years	5%	\$44
50-64 years	29%	\$1,093
65-74 years	19%	\$508
Overall	11%	\$6,243

Source: Primary data collected through the 2024 PD and Related Disorders Impact Survey, combined with average earnings from Bureau of Labor Statistics, and PD prevalence estimated by Lewin.

*May not sum to Overall row due to rounding.

Exhibit A 8. Percentage of Persons with Parkinson's Disease Employed in the Past 12 Months

	Total Population	% Employed
Males		
18-49 years	33,666	53%
50-64 years	143,686	44%
65-74 years	241,882	10%
≥75 years	256,928	4%
Females		
18-49 years	18,053	58%

	Total Population	% Employed
50-64 years	78,905	33%
65-74 years	98,279	8%
≥75 years	221,107	4%
Overall	1,092,506	15%

Source: Primary data collected through the 2024 PD and Related Disorders Impact Survey, combined with average earnings from Bureau of Labor Statistics, and PD prevalence estimated by Lewin.

Exhibit A 9. Estimated Productivity Loss Due to Parkinson's Related Absenteeism

	Average No. of Workdays Missed	Total Annual Absenteeism Cost (in Millions \$)*
Males		
18-49 years	3.6	\$374
50-64 years	4.0	\$1,546
65-74 years	2.7	\$287
≥75 years	4.7	\$248
Females		
18-49 years	6.1	\$400
50-64 years	4.0	\$476
65-74 years	2.2	\$70
≥75 years	1.1	\$38
Overall	3.8	\$3,439

Source: Primary data collected through the 2024 PD and Related Disorders Impact Survey, combined with average earnings from Bureau of Labor Statistics, and PD prevalence estimated by Lewin.

*May not sum to Overall row due to rounding.

Exhibit A 10. Estimated Productivity Loss Due to Parkinson's Related Presenteeism

	Average No. of Workdays Missed	Total Annual Presenteeism Cost (in Millions \$)*
Males		
18-49 years	12.2	\$396
50-64 years	11.4	\$1,353
65-74 years	7.0	\$231
≥75 years	8.5	\$138
Females		
18-49 years	12.0	\$244
50-64 years	12.5	\$460
65-74 years	6.0	\$60
≥75 years	5.6	\$63
Overall	10.4	\$2,944

	Average No. of Workdays Missed	Total Annual Presenteeism Cost (in Millions \$)*
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Source: Primary data collected through the 2024 PD and Related Disorders Impact Survey, combined with average earnings from Bureau of Labor Statistics, and PD prevalence estimated by Lewin.

*May not sum to Overall row due to rounding.

Exhibit A 11. Estimated Social Productivity Loss Due to Parkinson's Disease

	Percent PWPV Volunteered	Mean Change in Hours	Change in Hours, %	Total Annual Social Productivity Loss (in Millions \$)*
Males				
18-49 years	53%	8.6	71%	\$52
50-64 years	23%	7.4	65%	\$107
65-74 years	25%	4.3	61%	\$257
≥75 years	18%	3.8	44%	\$135
Females				
18-49 years	29%	5.9	49%	\$10
50-64 years	28%	8.5	68%	\$70
65-74 years	28%	3.8	64%	\$108
≥75 years	20%	4.5	81%	\$232
Overall	24%	5.4	63%	\$972

Source: Primary data collected through the 2024 PD and Related Disorders Impact Survey, combined with average earnings from Bureau of Labor Statistics, and AP prevalence estimated by Lewin.

*May not sum to Overall row due to rounding.

Disability Benefit Costs

Exhibit A 12. Estimated Disability Income Received by Persons with Parkinson's Disease 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 Millions \$)^
Males							
18-49 years	6%	\$11,604	10%	\$11,830	32%	45,101	\$554
50-64 years	6%	\$19,130	29%	\$24,407	19%	42,615	\$2,361
65-74 years	3%	\$19,948	14%	\$20,255	9%	46,479	\$1,835
≥75 years	5%	\$12,526	2%	\$13,234	12%	24,724	\$976
Females							
18-49 years	15%	\$12,852	23%	\$11,022	10%	22,818	\$120

	% 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 Millions \$)^
50-64 years	9%	\$12,325	32%	\$21,950	16%	42,085	\$1,183
65-74 years	9%	\$15,778	5%	\$17,836	4%	34,464	\$352
≥75 years	7%	\$15,236	3%	\$6,501	6%	39,119	\$767
Overall	6%	\$15,309	11%	\$20,390	11.1%	38,186	\$8,148

Source: Primary data collected through the 2024 PD and Related Disorders Impact Survey

*Annual other types of disability income (OTDI).

^May not sum to Overall row due to rounding.

Non-Medical Costs and Medical-Related Out-of-Pocket Expenses not Covered by Insurance

Exhibit A 13. Estimated Paid Daily Non-Medical Care Costs Due to Parkinson's Disease

	% Who Hired Someone to Provide Daily Care in the Past 12 Month	Average Cost (\$)	Total Cost of Paid Non-Medical Care (in Million \$)*
Males			
18-49 years	10%	\$567	\$1.8
50-64 years	8%	\$9,343	\$103
65-74 years	4%	\$3,522	\$31
≥75 years	12%	\$15,384	\$478
Females			
18-49 years	16%	\$8,510	\$25.2
50-64 years	15%	\$13,943	\$165
65-74 years	10%	\$16,265	\$162
≥75 years	15%	\$19,889	\$640
Overall	10%	\$14,456	\$1,607

Source: Primary data collected through the 2024 PD and Related Disorders Impact Survey.

*May not sum to Overall row due to rounding.

Total Economic Burden

Exhibit A 14. The Direct Medical Cost of Parkinson's Disease in 2024 by Type of Service and Population Characteristics

	Total Excess Medical Cost* Attributable to PD		Per Capita (\$)
	(in Million \$)	Percentage of the Total ^v	
Age			
18-49	\$633	3%	\$12,233
50-64	\$4,790	23%	\$21,519
65-74	\$6,510	31%	\$19,137
≥75	\$9,260	44%	\$19,370

	Total Excess Medical Cost* Attributable to PD		
	(in Million \$)	Percentage of the Total ^y	Per Capita (\$)
Gender			
Male	\$12,703	60%	\$18,392
Female	\$8,489	40%	\$19,847
Race/Ethnicity			
NH White	\$14,978	70%	\$18,218
NH Black	\$3,251	15%	\$27,056
Other	\$820	4%	\$14,390
Hispanic	\$2,318	11%	\$24,885
Insurance			
Private	\$1,689	8%	\$16,990
Medicare	\$17,836	86%	\$18,865
Medicaid	\$928	4%	\$40,685
Other^	\$245	1%	\$9,886
Type of service			
Non-acute Institutional Care	\$8,926	42%	\$8,171
Hospital Inpatient	\$4,661	22%	\$4,267
Hospital Outpatient	\$1,726	8%	\$1,580
Physician Office Visits/Ambulatory Care	\$3,832	18%	\$3,507
Durable Medical Equipment	\$235	1%	\$215
Prescription Medication	\$1,567	7%	\$1,434
Overall	\$21,368		\$19,559

Source: Lewin analyses of PD and AP prevalence using 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2024; combined with direct medical cost estimates using 2024 Optum dNHI administrative claims, 2023 Medicare Standard Analytical File 5% sample claims, 2022 Medicaid T-MSIS data, and 2022 Medicare Current Beneficiary Survey (MCBS).

*CPI adjusted to 2024 USD.

[^]Other includes other insurance not listed above such as Indian Health Services, Military, and uninsured.

[†]May not sum to Overall row due to rounding.

Exhibit A 15. The Indirect and Non-Medical Costs* of Parkinson's Disease in 2024 by Cost Component

	Total PWPDP Loss [^]	Per Capita PWPDP Loss
Indirect Costs		
Premature Death	\$2,855	\$2,613
Reduced Employment	\$36,243	\$5,715
Absenteeism	\$3,439	\$3,148
Presenteeism	\$2,944	\$2,695
Social Productivity Loss in Volunteer Work	\$972	\$889
Disability Income		
Supplemental security income (SSI)	\$984	\$901

	Total PWPDP Loss [^]	Per Capita PWPDP Loss
Social security disability insurance (SSDI)	\$2,526	\$2,312
Other disability income	\$4,638	\$4,245
Non-Medical Costs		
Paid daily non-medical care	\$1,607	\$1,471
Home modification	\$2,081	\$1,905
Motor vehicle modification	\$7,909	\$7,240
Other transportation expenses	\$168	\$153
One time purchase of home	\$666	\$610
Paid household help	\$3,758	\$3,440
Legal and financial	\$710	\$649
Respite for care partner	\$160	\$146
Out-of-pocket expenses not covered by insurance		
Products (over-the-counter and supplements)	\$687	\$629
Supplies (e.g., adaptive clothing, feeding equipment)	\$182	\$167
Therapeutic Activities (e.g., gym, exercise classes, online classes, home exercise equipment)	\$129	\$118
Counseling (patient education, psychotherapy, nutrition counseling, dietician) for PWPDP/AP and care partners)	\$4,109	\$3,761
Overall	\$46,766	\$42,807

Source: Lewin analyses of 2024 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 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2024. PWPDP is Person with Parkinson's disease.

*All costs in 2024 USD.

[^]May not sum to Overall row due to rounding.

Incidence of Parkinson's Disease

Exhibit A 16. Parkinson's Disease Incidence

	Incident* PD Cases	Person years	Incidence per 100,000 Person years
Age 18 to 64 years	3,136	16,570,172	18.9
Gender			
Male	1,851	7,840,138	23.6
Female	1,285	8,730,034	14.7
Race/ethnicity			
White	2,187	24,508,125	8.9
Black	348	7,855,824	4.4
Other	284	7,263,537	3.9

	Incident* PD Cases	Person years	Incidence per 100,000 Person years
Hispanic	297	7,794,360	3.8
Insurance			
Private	779	5,573,604	14.0
Medicare	172	270,844	63.5
Medicaid	1,822	9,473,651	19.2
Age ≥65 years	4,479	2,324,090	192.7
Gender			
Male	2,603	1,026,228	253.6
Female	1,876	1,297,862	144.5
Race/ethnicity			
White	2,083	1,008,228	206.6
Black	106	70,872	149.6
Other	177	80,707	219.3
Hispanic	25	17,506	142.8
Insurance			
Medicare	4,479	2,324,090	192.7

Source: Lewin analysis of Optum administrative claims data 2021-2024, Medicare SAF 5% 2022-2023, and Medicaid T-MSIS 2021-2022.

*Incidence ascertained by 24 months clean lookback without prior diagnosis of PD or AP.

Atypical Parkinsonism Results

Prevalence of Atypical Parkinsonism

Exhibit A 17. Atypical Parkinsonism Prevalence by Population Characteristics

	No. of Persons Estimated to Have AP	Population	Prevalence
Age			
18-49	5,097	141,792,556	0.004%
50-64	18,248	61,660,017	0.03%
65-74	36,537	35,223,309	0.10%
≥75	61,575	26,298,663	0.23%
Gender			
Male	67,969	130,227,394	0.05%
Female	53,488	134,747,151	0.04%
Race/Ethnicity			
NH White	92,067	161,154,757	0.06%
NH Black	17,988	31,955,514	0.06%
Other	5,337	24,560,303	0.02%
Hispanic	6,207	47,303,971	0.01%
Insurance			
Private	6,380	138,862,094	0.005%
Medicare	111,090	73,280,221	0.15%

	No. of Persons Estimated to Have AP	Population	Prevalence
Medicaid	2,607	28,432,466	0.01%
Other Insurance*	1,380	24,399,765	0.01%
Overall	121,457	264,974,545	0.05%

Source: Lewin analyses of 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2024.

*Other insurance includes other insurance not listed above such as Indian Health Services, Military, or uninsured.

Direct Medical Costs

Exhibit A 18. Direct Medical Cost of Atypical Parkinsonism by Age and Gender, 2024

	No. of Persons Estimated to Have AP	Total Excess Medical Cost Attributable to AP*		Mean Excess Cost due to AP (\$)
		Excess Cost (in Million \$)^	Percentage of Total	
Males				
18-49 years	2,693	\$70	2%	\$26,020
50-64 years	10,664	\$651	22%	\$61,018
65-74 years	24,750	\$455	15%	\$18,402
≥75 years	29,861	\$477	16%	\$15,990
Females				
18-49 years	2,403	\$79	3%	\$32,757
50-64 years	7,584	\$321	11%	\$42,352
65-74 years	11,787	\$275	9%	\$23,296
≥75 years	31,714	\$619	21%	\$19,505
Overall	121,457	\$2,947		\$24,262

Source: Lewin analyses of AP and AP prevalence using 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2024; combined with direct medical cost estimates using 2024 Optum claims, 2023 Medicare Standard Analytical File 5% sample claims, and 2022 Medicare Current Beneficiary Survey (MCBS).

*CPI adjusted to 2024 USD.

^May not sum to Overall row due to rounding.

Indirect Costs

Exhibit A 19. Estimated Number of Premature Deaths Associated with Atypical Parkinsonism in 2024

	AP Death Rate	Non-AP Death Rate	Difference in Rates (AP - non-AP)	Estimated Number of Premature Deaths for AP
Males				
18-49 years	0.7%	0.3%	0.5%	14
50-64 years	2.4%	1.0%	1.5%	169
65-74 years	6.8%	2.6%	4.3%	3,935

	AP Death Rate	Non-AP Death Rate	Difference in Rates (AP - non-AP)	Estimated Number of Premature Deaths for AP
Females				
18-49 years	1.1%	0.1%	1.0%	25
50-64 years	3.3%	0.6%	2.7%	205
65-74 years	5.9%	1.7%	4.2%	2,017

Source: Lewin analyses of 2022-2023 CDC WONDER multiple cause of deaths files and Medicare 5% sample claims data combined with Lewin estimates of prevalence.

Exhibit A 20. Estimated Net Present Value of Future Earnings Loss for Premature Deaths Associated with Atypical Parkinsonism

	Estimated Number of Premature Deaths	Estimated Present Value of Future Earnings/Death (\$)	Estimated NPV (in Million \$)*
Males			
18-49 years	14	\$1,195,551	\$16
50-64 years	169	\$428,159	\$72
65-74 years	3,935	\$69,940	\$275
Females			
18-49 years	25	\$1,020,494	\$25
50-64 years	205	\$353,358	\$72
65-74 years	2,017	\$49,481	\$100
Overall	6,364	\$88,220	\$561

Source: Lewin analyses of 2022-2023 CDC Wonder and 2023 Medicare 5% sample claims data. Death rates for ≥65 were derived from Medicare 5% data. Death rates for <65 non-AP population were derived from CDC WONDER data. Death rates for <65 AP population are estimated. Average earnings by age and gender obtained from Bureau of Labor Statistics.

* May not sum to Overall row due to rounding.

Exhibit A 21. Estimated Labor Market Earnings Loss due to Atypical Parkinsonism Related Unemployment

Gender Age Group	Percentage Retired and Stopped Working due to AP	Total Earnings Loss (in Million \$)*
Males		
18-49 years	0%	\$0
50-64 years	14%	\$82
65-74 years	26%	\$303
Females		
18-49 years	0%	\$0
50-64 years	30%	\$117
65-74 years	6%	\$34
Overall	9%	\$536

Source: Primary data collected through the 2024 PD and Related Disorders Impact Survey, combined with average earnings from Bureau of Labor Statistics, and AP prevalence estimated by Lewin.

*May not sum to Overall row due to rounding.

Exhibit A 22. Percentage of Persons with Atypical Parkinsonism Employed in the Past 12 Months

Gender Age Group	Total Population	% Employed
Males		
18-49 years	2,693	67%
50-64 years	10,664	27%
65-74 years	24,750	3%
≥75 years	29,861	5%
Females		
18-49 years	2,403	33%
50-64 years	7,584	26%
65-74 years	11,787	3%
≥75 years	31,714	11%
Overall	121,457	14%

Source: Primary data collected through the 2024 PD and Related Disorders Impact Survey.

Exhibit A 23. Estimated Productivity Loss Due to Atypical Parkinsonism Related Absenteeism

Gender Age Group	Average No. of Workdays Missed	Total Annual Absenteeism Cost (in Millions \$)*
Males		
18-49 years	5.0	\$54
50-64 years	5.3	\$77
65-74 years	21.0	\$97
≥75 years	5.0	\$37
Females		
18-49 years	7.0	\$16
50-64 years	3.9	\$31
65-74 years	0.0	\$0
≥75 years	2.5	\$36
Overall	4.7	348

Source: Primary data collected through the 2024 PD and Related Disorders Impact Survey, combined with average earnings from Bureau of Labor Statistics, and AP prevalence estimated by Lewin.

*May not sum to Overall row due to rounding.

Exhibit A 24. Estimated Productivity Loss Due to Atypical Parkinsonism Related Presenteeism

Gender Age Group	Average No. of Workdays Missed	Total Annual Presenteeism Cost (in Millions \$)*
Males		
18-49 years	20.0	\$67
50-64 years	21.0	\$94
65-74 years	12.0	\$17
≥75 years	30.5	\$69
Females		
18-49 years	4.0	\$3
50-64 years	14.0	\$35
65-74 years	30.0	\$32
≥75 years	1.3	\$6
Overall	12.1	\$323

Source: Primary data collected through the 2024 PD and Related Disorders Impact Survey.

*May not sum to Overall row due to rounding.

Exhibit A 25. Estimated Social Productivity Loss Due to Atypical Parkinsonism

Gender Age Group	Percent PWAP Volunteered	Mean Change in Hours	Change in Hours, %	Total Annual Social Productivity Loss (in Millions \$)^
Males				
18-49 years	67%	15.0	75%	\$6
50-64 years	23%	15.7	75%	\$9
65-74 years	25%	NA*	NA*	\$0
≥75 years	18%	25.5	84%	\$30
Females				
18-49 years	29%	NA*	NA*	\$0
50-64 years	28%	10.1	72%	\$7
65-74 years	28%	30.0	100%	\$20
≥75 years	20%	NA ⁸	NA*	\$0
Overall	23%	8.9	63%	\$72

Source: Primary data collected through the 2024 PD and Related Disorders Impact Survey, combined with average earnings from Bureau of Labor Statistics, and AP prevalence estimated by Lewin.

*Due to small cell sizes for age-gender stratum reporting volunteer hours, we are unable to estimate change in volunteer hours.

^May not sum to Overall row due to rounding.

Disability Benefit Costs

Exhibit A 26. Estimated Disability Income Received by Persons with Atypical Parkinsonism 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 Millions \$)^
Males							
18-49 years	25%	NA	25%	NA	50%	\$7,506	\$10
50-64 years	8%	\$25,850	42%	\$17,016	13%	\$30,004	\$139
65-74 years	4%	\$35,750	21%	\$18,000	6%	\$38,000	\$192
≥75 years	5%	NA	2%	\$45,000	7%	\$11,348	\$48
Females							
18-49 years	19%	\$24,800	19%	\$3,604	0%	NA	\$13
50-64 years	16%	\$13,094	30%	\$23,942	11%	\$40,055	\$104
65-74 years	9%	\$10,157	6%	\$22,848	3%	\$11,806	\$32
≥75 years	7%	\$24,200	6%	\$8,438	6%	\$2,650	\$74
Overall	8%	\$16,632	13%	\$22,213	8%	\$17,673	\$612

Source: Primary data collected through the 2024 PD and Related Disorders Impact Survey.

*Annual other types of disability income (OTDI).

^May not sum to Overall row due to rounding.

Non-Medical Costs and Medical-Related Out-of-Pocket Expenses not Covered by Insurance

Exhibit A 27. Estimated Paid Daily Non-Medical Care Costs Due to Atypical Parkinsonism

	% of PWAPs Who Hired Someone to Provide Daily Care in the Past 12 Month	Average Cost (\$)	Total Cost of Paid Non-Medical Care (in Million \$)*
Males			
18-49 years	25%	\$6,000	\$4.0
50-64 years	13%	\$8,667	\$12
65-74 years	6%	\$6,374	\$10
≥75 years	23%	\$18,792	\$130
Females			
18-49 years	50%	\$30,300	\$36.4
50-64 years	32%	\$31,735	\$76
65-74 years	29%	\$14,978	\$52
≥75 years	27%	\$26,381	\$224
Overall	21%	\$20,878	\$545

Source: Primary data collected through the 2024 PD and Related Disorders Impact Survey. PWAP is Person with Atypical Parkinsonism.

*May not sum to Overall row due to rounding.

Total Economic Burden**Exhibit A 28. Total and Per Capita Direct Medical Cost of Atypical Parkinsonism in 2024 by Type of Service and Population Characteristics**

	Total Excess Medical Cost* Attributable to AP		Per Capita (\$)
	(in Million \$)^	Percentage of the Total	
Age			
18-49	\$149	5%	\$29,197
50-64	\$972	33%	\$53,260
65-74	\$730	25%	\$19,981
≥75	\$1,096	37%	\$17,800
Gender			
Male	\$1,654	56%	\$24,331
Female	\$1,293	44%	\$24,175
Race/Ethnicity			
NH White	\$1,614	55%	\$1,765
NH Black	\$398	13%	\$2,879
Hispanic	\$74	3%	\$1,194
Other	\$135	5%	\$1,359
Insurance			
Private	\$148	5%	\$22,671
Medicare	\$2,229	76%	\$24,811
Medicaid	\$552	19%	
Other Insurance ^γ	\$17	1%	\$19,489
Type of service			
Non-acute Institutional Care	\$1,245	41%	\$10,253
Hospital Inpatient	\$819	27%	\$6,744
Hospital Outpatient	\$183	6%	\$1,507
Office Visit/Ambulatory Care	\$333	11%	\$2,746
Durable Medical Equipment	\$59	2%	\$484
Prescription Medication	\$396	13%	\$3,262
Overall	\$3,036		\$24,996

Source: Lewin analyses of PD and AP prevalence using 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2024; combined with direct medical cost estimates using 2024 Optum dNHI administrative claims, 2023 Medicare Standard Analytical File 5% sample claims, 2022 Medicaid T-MSIS data, and 2022 Medicare Current Beneficiary Survey (MCBS).

*CPI adjusted to 2024 USD.

^May not sum to Overall row due to rounding.

^γOther insurance includes other insurance not listed above such as Indian Health Services, Military, and uninsured.

Exhibit A 29. Total and Per Capita Indirect Costs*, Disability Income, Non-Medical and Out-of-Pocket Expenses not Covered by Insurance

	Total PWAP Loss [^]	Per Capita PWAP Loss
Indirect Costs		

	Total PWAP Loss [^]	Per Capita PWAP Loss
Premature Death	\$549	\$4,520
Reduced Employment	\$536	\$4,410
Absenteeism	\$348	\$2,866
Presenteeism	\$323	\$2,660
Social Productivity Loss in Volunteer Work	\$72	\$592
Disability Income		
Supplemental security income (SSI)	\$152	\$1,254
Social security disability insurance (SSDI)	\$283	\$2,331
Other disability income	\$176	\$1,452
Non-Medical Costs		
Paid daily non-medical care	\$545	\$4,485
Home modification	\$258	\$2,121
Motor vehicle modification	\$534	\$4,394
Other transportation expenses	\$13	\$106
One time purchase of home	\$69	\$567
Paid household help	\$201	\$1,654
Legal and financial	\$73	\$602
Respite for care partner	\$41	\$334
Out-of-pocket expenses not covered by insurance		
Products (over-the-counter and supplements)	\$657	\$5,408
Supplies (e.g., adaptive clothing, feeding equipment)	\$35	\$292
Therapeutic Activities (e.g., gym, exercise classes, online classes, home exercise equipment)	\$0	\$0
Counseling (patient education, psychotherapy, nutrition counseling, dietician) for PWPD/AP and care partners)	\$53	\$435
Overall	\$4,944	\$40,703

Source: Lewin analyses of 2024 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 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2024. PWPD/AP is Person with Parkinson's disease/Parkinson's Related Disorders.

*All costs in 2024 USD.

[^]May not sum to Overall row due to rounding.

Incidence of Atypical Parkinsonism

Exhibit A 30. Atypical Parkinsonism Incidence Rates per 100,000 Population

	Incident* PD Cases	Person years	Incidence per 100,000 Person years
Age 18 to 64 years	454	16,570,172	2.7
Gender			
Male	237	7,840,138	3.0
Female	217	8,730,034	2.5
Race/ethnicity			

	Incident* PD Cases	Person years	Incidence per 100,000 Person years
White	457	24,508,125	1.9
Black	93	7,855,824	1.2
Other	38	7,263,537	0.5
Hispanic	51	7,794,360	0.7
Insurance			
Private	134	5,573,604	2.4
Medicare	24	270,844	8.9
Medicaid	218	9,473,651	2.3
Age ≥65 years	968	2,324,090	41.7
Gender			
Male	492	1,026,228	47.9
Female	476	1,297,862	36.7
Race/ethnicity			
White	415	1,008,228	41.2
Black	15	70,872	21.2
Other	17	80,707	21.1
Hispanic	4	17,506	22.8
Insurance			
Medicare	968	2,324,090	41.7

Source: Lewin analysis of Optum administrative claims data 2021-2024, Medicare SAF 5% 2022-2023, and Medicaid T-MSIS 2021-2022.

*Incidence ascertained by 24 months clean lookback without prior diagnosis of PD or AP.

Comparison Group

Exhibit A 31. Comparison of Per-Capita Cost* Between PD/AP and Comparison groups, by Age, Gender, and Insurance Type

Insurance	Age Group	Gender	N	Per-PWPD/AP (\$)	Per-Comparison Person (\$)
Private	18-49	Male	-	\$20,043	\$6,242
		Female	17,563	\$37,275	\$8,799
	50-64	Male	57,543	\$23,406	\$13,098
		Female	30,697	\$22,804	\$12,990
Medicare	18-49	Male	36,359	\$42,571	\$18,670
		Female	2,893	\$38,726	\$22,309
	50-64	Male	66,961	\$53,569	\$24,739
		Female	34,020	\$50,495	\$24,868
	65-74	Male	266,632	\$36,155	\$16,439
		Female	110,066	\$34,463	\$16,205
	≥75	Male	286,790	\$39,888	\$22,654
		Female	252,821	\$42,993	\$21,926

Insurance	Age Group	Gender	N	Per-PWPD/AP (\$)	Per-Comparison Person (\$)
Medicaid	18-49	Male	-	\$45,990	\$2,829
		Female	-	\$35,205	\$5,720
	50-64	Male	19,091	\$44,197	\$2,259
		Female	6,337	\$35,104	\$5,187
Other Insurance^	18-49	Male	-	\$14,306	\$4,455
		Female	-	\$26,606	\$6,280
	50-64	Male	10,755	\$16,707	\$9,349
		Female	15,435	\$16,277	\$9,272

Source: Lewin analyses of PD prevalence using 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2024; combined with direct medical cost estimates using 2024 Optum claims, 2023 Medicare Standard Analytical File 5% sample claims, 2022 Medicaid T-MSIS data, and 2022 Medicare Current Beneficiary Survey (MCBS).

*CPI adjusted to 2024 USD.

^Other insurance includes other insurance not listed above such as Indian Health Services, Military, and uninsured.

Survey Sample Characteristics

Response Rates

Exhibit A 32. Survey Response Rates

	Total		Fox Insight		Lewin Qualtrics	
Date of Launch			4/24/2025		5/14/2025	
Date of Close or Data Extract			6/9/2025		6/16/2025	
Impressions*	10,834*		1,541		9,293	
Respondents	7,355	100%	1,541		5,814	
Responded to first question	7,193	97.8%	1,541	100%	5,652	97.2%
PWPD/AP or Unpaid Care Partner	6,691	90.6%	1,309	84.9%	5,382	92.6%
PWPD/AP or Unpaid Care Partners after reconciling write-in answers	6,616	90.0%	1,302	84.5%	5,314	91.4%
Exclude missing demographics necessary for economic burden calculations^	829	12.5%	238	18.3%	591	11.1%
Exclude missing answers after year diagnosed question^	204	3.1%	16	1.2%	188	3.5%
Final sample	4,583	62.3%	1,066	69.2%	3,517	60.5%

*How many people opened the link/interacted with survey at all, even if they did not respond to any questions

^Exclusions not mutually exclusive

Exhibit A 33. Survey Respondents by Role and Diagnosis

Respondent	N	%
PWPD/AP	3,664	79.9%

	N	%
Care Partner	919	20.1%
Diagnosis best fits*		
Parkinson's disease	4,224	92.2%
Any AP	359	7.8%
Dementia with Lewy bodies	61	1.3%
Progressive Supranuclear Palsy	79	1.7%
Multiple system atrophy	44	1.0%
Corticobasal degeneration/syndrome	16	0.3%
Vascular parkinsonism	9	0.2%
Parkinsonism otherwise not specified	150	3.3%
Total	4,583	

Demographics and Sample Characteristics

Exhibit A 34. Demographic Characteristics of Survey Sample

	PWPD		PWAP		Care Partner	
	N	%	N	%	N	%
Total	3,470	100.0%	194	100.0%	919	100.0%
Age Group						
18-49	68	2.0%	6	3.1%	38	4.1%
50-64	761	21.9%	49	25.3%	187	20.3%
65-74	1,490	42.9%	65	33.5%	357	38.8%
≥75	1,151	33.2%	74	38.1%	337	36.7%
Gender						
Male	1,903	54.8%	93	47.9%	271	29.5%
Female	1,567	45.2%	101	52.1%	648	70.5%
Race						
White	3,215	92.7%	178	91.8%	856	93.1%
African American	37	1.1%	1	0.5%	14	1.5%
American Indian	16	0.5%	1	0.5%	5	0.5%
Asian	46	1.3%	3	1.5%	11	1.2%
Other	3	0.1%	0	0.0%	1	0.1%
Prefer not to answer	43	1.2%	8	4.1%	20	2.2%
Ethnicity						
Not Hispanic	3,166	91.2%	175	90.2%	857	93.3%
Hispanic	82	2.4%	7	3.6%	18	2.0%
Mexican	5	0.1%	1	0.5%	1	0.1%
Puerto Rican	22	0.6%	2	1.0%	8	0.9%
Cuban	9	0.3%	0	0.0%	2	0.2%
Latino	46	1.3%	4	2.1%	7	0.8%
Prefer not to answer	74	2.1%	5	2.6%	22	2.4%

Source: Primary data collected through the 2024 PD and Related Diagnosis Impact Survey. PWPDP is Person with Parkinson's Disease, PWAP is Person with Atypical Parkinsonism.

Exhibit A 35. Marital status of the persons with Parkinson's and unpaid care partners

	PWPDP		PWAP		Care Partner	
	N	%	N	%	N	%
Total	3,470	100.0%	194	100.0%	919	100.0%
Marital status						
Married/living with partner	2,627	75.7%	133	68.6%	834	90.8%
Widowed	279	8.0%	20	10.3%	46	5.0%
Divorced/separated	361	10.4%	26	13.4%	24	2.6%
Never married	159	4.6%	13	6.7%	13	1.4%
Don't know	12	0.3%	0	0.0%	1	0.1%
Prefer not to answer	32	0.9%	2	1.0%	1	0.1%

Source: Primary data collected through the 2024 PD and Related Diagnosis Impact Survey. PWPDP is Person with Parkinson's Disease, PWAP is Person with Atypical Parkinsonism.

Exhibit A 37. Total household earnings for PWPDP/AP in the most recent tax year

	PWPDP		PWAP		Care Partner	
	N	%	N	%	N	%
Overall	3,470	100.0%	194	100.0%	919	100.0%
Household earnings						
<\$25,000	330	9.5%	32	16.5%	76	8.3%
\$25,000 to < \$50,000	450	13.0%	27	13.9%	105	11.4%
\$50,000 to < \$75,000	491	14.1%	26	13.4%	159	17.3%
\$75,000 to < \$100,000	497	14.3%	28	14.4%	158	17.2%
\$100,000 to < \$125,000	362	10.4%	22	11.3%	95	10.3%
\$125,000 to < \$150,000	280	8.1%	15	7.7%	62	6.7%
\$150,000 to < \$175,000	139	4.0%	7	3.6%	38	4.1%
\$175,000 to < \$200,000	131	3.8%	6	3.1%	30	3.3%
More than \$200,000	414	11.9%	15	7.7%	88	9.6%
Prefer not to answer	362	10.4%	16	8.2%	76	8.3%

Note: The total earnings include 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 PWPDP, and excludes co-residents who are financially independent and all paid care partners who are not family members. PWPDP is Person with Parkinson's Disease, PWAP is Person with Atypical Parkinsonism.

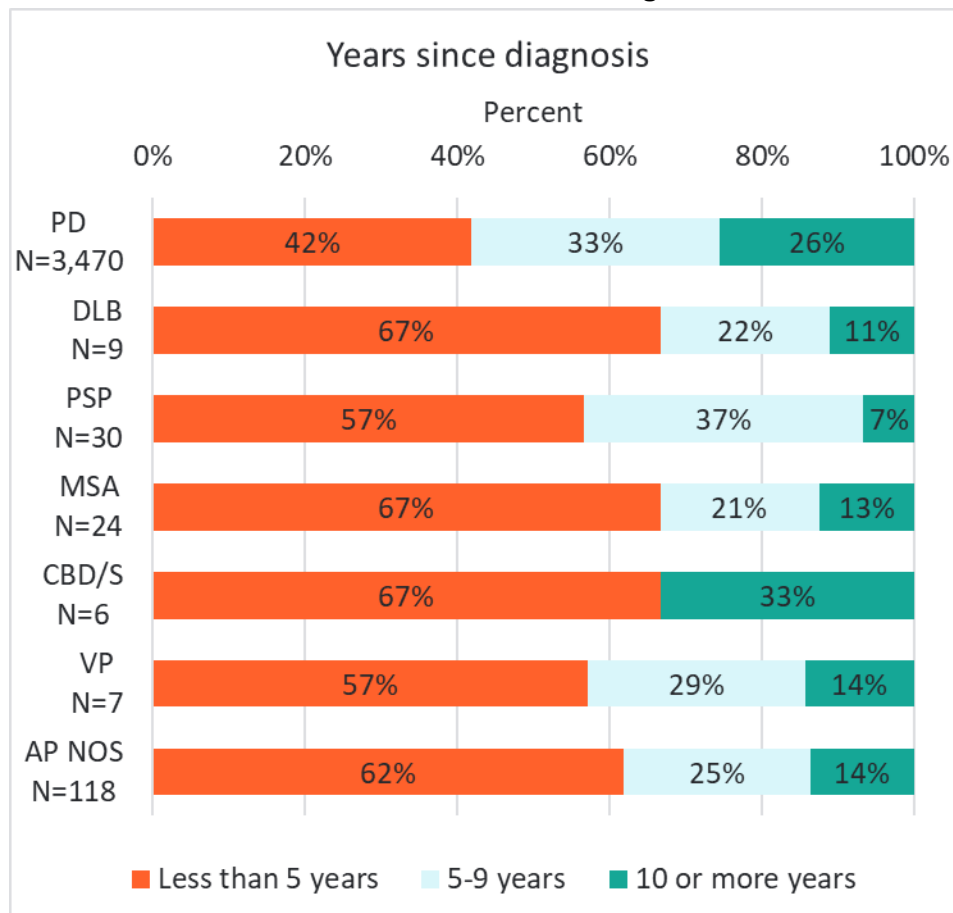
Exhibit A 37. Veteran Status of Survey Sample

	PWPDP		PWAP		Care Partner	
	N	%	N	%	N	%

Overall	3,470	100.0%	194	100.0%	919	100.0%
Veteran	524	15.1%	22	11.3%	92	10.0%

Source: Primary data collected through the PD and Related Diagnosis Impact Survey. PWPD is Person with Parkinson's Disease, PWAP is Person with Atypical Parkinsonism.

Exhibit A 38. Years Since Diagnosis



Source: Primary data collected through the PD and Related Diagnosis Impact Survey.

Exhibit A 39. Symptom Severity for Persons with Parkinson's and Atypical Parkinsonism

		PWPD		PWAP	
		Frequency	Percent	Frequency	Percent
Total		3,470		194	
Slowed movement	Did not experience	389	11.2%	19	9.8%
	Mild	1,747	50.3%	65	33.5%
	Moderate	1,199	34.6%	87	44.8%
	Severe	135	3.9%	23	11.9%
Tremors	Did not experience	544	15.7%	61	31.4%
	Mild	1,856	53.5%	76	39.2%

		PWPD		PWAP	
		Frequency	Percent	Frequency	Percent
	Moderate	963	27.8%	47	24.2%
	Severe	107	3.1%	10	5.2%
Poor balance and condition	Did not experience	543	15.6%	12	6.2%
	Mild	1,606	46.3%	59	30.4%
	Moderate	1,040	30.0%	67	34.5%
	Severe	281	8.1%	56	28.9%
Orthostatic hypotension	Did not experience	1,561	45.0%	77	39.7%
	Mild	1,389	40.0%	55	28.4%
	Moderate	432	12.4%	49	25.3%
	Severe	88	2.5%	13	6.7%
Trouble speaking	Did not experience	1,381	39.8%	52	26.8%
	Mild	1,539	44.4%	73	37.6%
	Moderate	451	13.0%	48	24.7%
	Severe	99	2.9%	21	10.8%
Trouble writing	Did not experience	736	21.2%	28	14.4%
	Mild	1,446	41.7%	58	29.9%
	Moderate	877	25.3%	64	33.0%
	Severe	411	11.8%	44	22.7%
Urinary issues such as urinary urgency or loss of bladder control	Did not experience	978	28.2%	48	24.7%
	Mild	1,456	42.0%	67	34.5%
	Moderate	828	23.9%	54	27.8%
	Severe	208	6.0%	25	12.9%
Gastrointestinal issues such as constipation or irritable bowel syndrome	Did not experience	873	25.2%	49	25.3%
	Mild	1,245	35.9%	55	28.4%
	Moderate	1,068	30.8%	68	35.1%
	Severe	284	8.2%	22	11.3%
Sleep issues (such as trouble falling asleep, staying asleep, abnormal dreams, etc.)	Did not experience	487	14.0%	22	11.3%
	Mild	1,281	36.9%	63	32.5%
	Moderate	1,288	37.1%	70	36.1%
	Severe	414	11.9%	39	20.1%
Fatigue and loss of energy	Did not experience	372	10.7%	20	10.3%
	Mild	1,447	41.7%	55	28.4%
	Moderate	1,317	38.0%	82	42.3%
	Severe	334	9.6%	37	19.1%
Difficulty with concentrating	Did not experience	1,111	32.0%	44	22.7%
	Mild	1,625	46.8%	83	42.8%
	Moderate	637	18.4%	48	24.7%
	Severe	97	2.8%	19	9.8%
	Did not experience	962	27.7%	42	21.6%
	Mild	1,679	48.4%	81	41.8%

		PWPD		PWAP	
		Frequency	Percent	Frequency	Percent
Difficulty with memorizing or recalling information	Moderate	710	20.5%	58	29.9%
	Severe	119	3.4%	13	6.7%
Difficulty with understanding requirements to complete complex tasks	Did not experience	1,794	51.7%	79	40.7%
	Mild	1,171	33.7%	71	36.6%
	Moderate	438	12.6%	37	19.1%
	Severe	67	1.9%	7	3.6%
Drooling	Did not experience	1,734	50.0%	94	48.5%
	Mild	1,370	39.5%	69	35.6%
	Moderate	302	8.7%	22	11.3%
	Severe	64	1.8%	9	4.6%
Difficulty with swallowing	Did not experience	1,743	50.2%	73	37.6%
	Mild	1,357	39.1%	81	41.8%
	Moderate	329	9.5%	33	17.0%
	Severe	41	1.2%	7	3.6%
Vision problems	Did not experience	1,623	46.8%	58	29.9%
	Mild	1,341	38.6%	69	35.6%
	Moderate	425	12.2%	52	26.8%
	Severe	81	2.3%	15	7.7%
Pain	Did not experience	678	19.5%	31	16.0%
	Mild	1,479	42.6%	69	35.6%
	Moderate	1,058	30.5%	64	33.0%
	Severe	255	7.3%	30	15.5%
Anxiety	Did not experience	1,173	33.8%	65	33.5%
	Mild	1,398	40.3%	66	34.0%
	Moderate	743	21.4%	48	24.7%
	Severe	156	4.5%	15	7.7%
Depression	Did not experience	1,571	45.3%	67	34.5%
	Mild	1,219	35.1%	66	34.0%
	Moderate	539	15.5%	48	24.7%
	Severe	141	4.1%	13	6.7%
Apathy	Did not experience	1,286	37.1%	60	30.9%
	Mild	1,468	42.3%	66	34.0%
	Moderate	579	16.7%	53	27.3%
	Severe	137	3.9%	15	7.7%
Hallucinations or delusions	Did not experience	2,821	81.3%	136	70.1%
	Mild	516	14.9%	44	22.7%
	Moderate	117	3.4%	12	6.2%
	Severe	16	0.5%	2	1.0%
Falls	Did not experience	2,262	65.2%	82	42.3%
	Mild	744	21.4%	57	29.4%

		PWPD		PWAP	
		Frequency	Percent	Frequency	Percent
	Moderate	351	10.1%	38	19.6%
	Severe	113	3.3%	17	8.8%

Source: Primary data collected through the PD and Related Diagnosis Impact Survey. PWPD is Person with Parkinson's Disease, PWAP is Person with Atypical Parkinsonism.

Appendix B. State Level Prevalence

Exhibit B 1. Prevalence of Parkinson's Disease or Atypical Parkinsonism by state in 2024

State	Number of Individuals with Diagnosed PD or AP	Number of Individuals with Diagnosed PD	2024 US Population (Age 18+)	PD or AP Prevalence (Per 1000 Population)	PD Prevalence (Per 1000 Population)
Alabama	18,582	16,113	3,974,033	4.68	4.05
Alaska	2,213	2,026	549,793	4.02	3.68
Arizona	28,371	25,210	5,758,622	4.93	4.38
Arkansas	10,678	9,789	2,374,087	4.50	4.12
California	133,806	123,644	30,961,361	4.32	3.99
Colorado	20,895	17,734	4,782,737	4.37	3.71
Connecticut	14,847	13,370	2,946,006	5.04	4.54
Delaware	4,320	3,678	833,518	5.18	4.41
District of Columbia	1,916	1,914	562,938	3.40	3.40
Florida	100,441	83,717	18,633,609	5.39	4.49
Georgia	39,510	36,268	8,716,102	4.53	4.16
Hawaii	6,135	5,149	1,139,637	5.38	4.52
Idaho	6,771	6,034	1,523,249	4.44	3.96
Illinois	44,926	41,416	10,077,020	4.46	4.11
Indiana	24,872	21,734	5,365,523	4.64	4.05
Iowa	11,744	10,402	2,520,658	4.66	4.13
Kansas	10,151	8,929	2,259,320	4.49	3.95
Kentucky	16,794	14,939	3,523,884	4.77	4.24
Louisiana	15,466	14,463	3,509,803	4.41	4.12
Maine	6,858	5,621	1,179,861	5.81	4.76
Maryland	22,191	20,833	4,956,671	4.48	4.20
Massachusetts	24,918	23,655	5,662,456	4.40	4.18
Michigan	36,845	33,041	7,965,890	4.63	4.15
Minnesota	21,135	18,711	4,603,353	4.59	4.06
Mississippi	10,638	9,646	2,280,422	4.66	4.23
Missouri	22,072	20,290	4,818,247	4.58	4.21
Montana	4,570	3,707	916,592	4.99	4.04
Nebraska	7,167	6,153	1,512,605	4.74	4.07
Nevada	11,746	10,417	2,596,150	4.52	4.01
New Hampshire	6,053	5,346	1,142,783	5.30	4.68
New Jersey	35,024	31,721	7,418,183	4.72	4.28
New Mexico	8,040	6,960	1,662,074	4.84	4.19
New York	71,120	64,393	15,624,820	4.55	4.12
North Carolina	40,952	36,580	8,629,642	4.75	4.24
North Dakota	2,528	2,263	609,969	4.14	3.71
Ohio	45,067	39,255	9,167,025	4.92	4.28

State	Number of Individuals with Diagnosed PD or AP	Number of Individuals with Diagnosed PD	2024 US Population (Age 18+)	PD or AP Prevalence (Per 1000 Population)	PD Prevalence (Per 1000 Population)
Oklahoma	13,134	12,173	3,061,819	4.29	3.98
Oregon	16,676	14,045	3,483,951	4.79	4.03
Pennsylvania	48,783	43,843	10,230,731	4.77	4.29
Rhode Island	4,084	3,663	877,798	4.65	4.17
South Carolina	20,702	18,136	4,288,080	4.83	4.23
South Dakota	3,243	2,805	690,051	4.70	4.07
Tennessee	24,940	23,018	5,618,408	4.44	4.10
Texas	90,280	87,719	23,190,716	3.89	3.78
Utah	9,250	8,914	2,530,815	3.65	3.52
Vermont	2,730	2,302	531,694	5.13	4.33
Virginia	32,081	28,678	6,896,817	4.65	4.16
Washington	27,232	24,967	6,364,913	4.28	3.92
West Virginia	7,628	6,222	1,424,869	5.35	4.37
Wisconsin	21,685	19,049	4,578,364	4.74	4.16
Wyoming	2,152	1,854	446,879	4.82	4.15
U.S. Total (age 18+)	1,213,963	1,092,506	264,974,545	4.58	4.12

Source: Lewin analyses of PD prevalence using 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projection for each state in 2024. National PD prevalence rates were extrapolated to state population by age and gender.

Appendix C. Code Lists

Exhibit C 1. Anti-Parkinson's Specific Treatments

Drug Class or Molecule (Brand Name)
Apomorphine (Apokyn)
Trihexyphenidyl (Artane or Apo-Trihex)
Rasagiline (Azilect)
Amantadine Extended Release (Gocovri ER or Osmolex ER)
Benzotropine (Cogentin)
Entacapone (Comtan)
((Sold in EU: Levodopa / Benserazide Immediate Release (Madopar or Prolopa)
((Sold in EU: Levodopa / Benserazide Controlled Release (Madopar CR, Madopar HBS, or Prolopa CR)
((Sold in EU: Levodopa / Benserazide Dispersible (Madopar Rapid)))
Cogentin (Benzotropine)
Selegiline (Deprenyl, Eldepryl, Zelapar)
Northera (Droxidopa)
Carbidopa / Levodopa Intestinal Gel (Duopa or Duodopa)
Selegiline (Eldepryl)
Selegiline Transdermal (Emasm)
Ropinirole Transdermal Patch (Haruropi Tape or HP-3000)
Carbidopa / Levodopa Inhalation Powder (Inbrija)
Apomorphine sublingual film (Kynmobi)
Carbidopa / Levodopa and Entacapone Intestinal Gel (Lecigon)
Carbidopa (Lodosyn)
Levodopa-benserazide
Pramipexole (Mirapex)
Pramipexole Extended Release or modified release tablets (Mirapex ER or Sifrol ER or Pramipexole XR GP)
Rotigotine (Neupro Patch)
Istradefylline (Nourianz or Nourias)
Nuplazid (Pimavanserin)
Opicapone (Ongentys)
Carbidopa / Levodopa Orally Disintegrating Tablets (Parcopa)
Bromocriptine (Parlodel)
Ethopropazine (Parsitan or Parsidan or Profenamine or Parsidol, or Parkin)
Ropinirole (Requip or Adartel)
Ropinirole Extended Release (Requip XL)
Carbidopa / Levodopa Extended Release Capsules (Rytary or Numient, Crexont)
Carbidopa / Levodopa Controlled Release (Sinemet CR)
Carbidopa / Levodopa Immediate Release (Sinemet, Dhivy)
Carbidopa / Levodopa and Entacapone (Stalevo)
Amantadine (Symmetrel)
Tolcapone (Tasmar)

Foscarbidopa/foslevodopa pump (Vyalev)
Safinamide (Xadago or Eufina)
Mucuna Pruriens
Pergolide Mesylate

Exhibit C 2. Anti-DLB Specific Treatments

Drug Class or Molecule	Brand Name
Donepezil	Aricept
Galantamine	Razadyne
Galantamine	Reminyl
Memantine	Namenda or Namenda XR
Memantine	Ebixa
Rivastigmine	Exelon

Exhibit C 3. Prodromal Diagnoses

Prodromal Condition	ICD-10-CM Diagnosis Code*
Mild cognitive impairment	G31.84
Major depressive disorder	F33
Olfactory dysfunction, hyposmia	R43.8
Orthostatic hypotension	I95.1
Tremor disorders	G25.0 G25.2
Speech impairment	R47
Gait disorders	F26
Constipation	K59
Mood disorder	F30 F31 F32 F34 F39
Anxiety	F41
Fatigue	R53

*unless otherwise specified, ICD-10 codes were rolled up to three-digits.

Appendix D. Equation Map for Calculating Indirect and Non-medical Costs from Survey

Cost Component	Equation using survey responses and derived variables	Variable	Fox Insight Variable Name
Reduced labor force participation for PWP/AD or care partners	Only applies to PWP/AD or care partners who retired early or stopped working for reasons related to their disease: Reduced Labor Force Participation = (Individual's current age) – (Age left workforce, if they answered that disease played a major role in their early retirement)*Median annual earnings from BLS for specific age-gender stratum	Current job status = retired or not working	FncImpJobStat
		Disease played a role = yes	FncImpWrkDcsn
		Current age	Age_current
		Age left workforce	FncImpYrRtrd
		Median annual earnings in 2024 from BLS	
Reduced earnings	Only applies to PWP/AD or care partners who are still working: Absenteeism = days missed in an average month * average number of months employed past year * average daily earnings Presenteeism = days less productive in an average month * average number of months employed past year * adjustment factor * average daily earnings Daily Earnings = Annual earnings / months employed past year / 30.25	Current job status = part or full-time	FncImpJobStat
		months employed past year	FncImpMnthsEmplyd
		Days missed work	FncImpDaysMssdWrk
		months employed past year	FncImpMnthsEmplyd
		Adjustment factor from earnings for PD and non-PD populations in MEPS	Derived from MEPS
		Days felt less productive	FncImpDaysLessPrdctve
		months employed past year	FncImpMnthsEmplyd
Social productivity	For individuals who are working: Social Productivity Loss = (Hours affected [BEFORE hours – AFTER hours]) * average hourly income for age-gender stratum * value of leisure time * 52	Annual earnings (using mid-point for each category)	FncImpHseHldEarn
		Current job status = part or full-time	FncImpJobStat
		Before hours	SocProdBefore
		After hours	SocProdAfter

Cost Component	Equation using survey responses and derived variables	Variable	Fox Insight Variable Name
	Average Hourly Income = Median hourly earnings for age-gender stratum	Median annual earnings in 2024 from BLS	Derived from Median weekly earnings of full-time wage and salary workers by selected characteristics : U.S. Bureau of Labor Statistics
		Value of leisure time	From CPS Supplement on Volunteering and Civic Life
	For those who are no longer in the workforce: Social Productivity Loss = (Hours affected [BEFORE hours – AFTER hours]) * 52 * (the average hourly value placed on volunteering) *Backup question to provide the number of hours spent by care partners on providing care.	Before hours	SocProdBefore
		After hours	SocProdAfter
		Average hourly value placed on volunteering	From Independent Sector Report on Value of Volunteer Time
		Year started providing care	Years Providing Care
Disability income	This only applies to individuals who responded that they are receiving at least one type of disability income:	Received any disability income = yes	FncImpDsbltyIncmeSSI FncImpDsbltyIncmeSSDI FncImpDsbltyIncmeOthr
		Supplemental Security Income (SSI)	FncImpDsbltyIncmeSSIAMnt
	Disability income = SSI + SSDI + OTDI	Social Security Disability Insurance (SSDI)	FncImpDsbltyIncmeSSDIAMnt
		Other types of disability income (OTDI)	FncImpDsbltyIncmeOthrAmnt
Out-of-pocket (OOP) costs (not covered by insurance)	Medical Care OOP (not covered by insurance) = Prescriptions + Products + Supplies + DME + Activities + Counseling	Prescriptions	FncImpAmntSpntAllPrscrptns
		Products (OTC and supplements)	FncImpAmntSpntProducts
		Supplies (adaptive clothing, feeding equipment)	FncImpAmntSpntSupplies
		Durable medical equipment	FncImpAmntSpntMedEqpmt
		Activities (gym, exercise classes, online classes, home exercise equipment)	FncImpAmntSpntActvts

Cost Component	Equation using survey responses and derived variables	Variable	Fox Insight Variable Name
	Expenses related to facilities should be weighted by number of months spent in respective facility	Counseling (patient education, psychotherapy, nutrition counseling, dietician) for PWP/AD and care partners	FncImpAmntSpntCnsIng
		Months in rehab facility	FncImpAmntMnthsOutptRehFclty
		Months in hospice	FncImpAmntMnthsHspce
		Months in nursing home	FncImpAmntMnthsNrsngHme
		Months in SNF	FncImpAmntMnthsSkldNrsngFac
		Months in other longterm care	FncImpAmntMnthsOthr
		Adult outpatient rehab facility expenses	FncImpAmntMnyOutptRehFclty
		Hospice facility expenses	Q28_4_1
		Nursing home expenses	FncImpAmntMnyNrsngHme
		Skilled nursing facility expenses	FncImpAmntMnySkldNrsngFac
		Other long term care expenses	FncImpAmntMnyOthr
Formal non-medical care	Annual Formal Non-Medical Care = Expenses to hire someone to provide daily assistance	Expenses to hire someone (e.g. a professional, relative, or friend) to provide daily care	FncImpAmntSpntPDCreHrSmnDlyCr
Non-medical costs	Non-Medical Costs = Motor vehicle modification + Paid non-medical household help + Home modifications +	Expenses related to purchasing a special vehicle or purchasing/installing special equipment on a car or other motor vehicle	FncImpAmntSpntPDCreHmeMod

Cost Component	Equation using survey responses and derived variables	Variable	Fox Insight Variable Name
	Paid daily non-medical care + Financial and legal planning + One-time accessible home purchase expenses + Respite for care partner + Other increased transportation expenses	Expenses to hire someone to do household chores/provide services other than patient care (e.g., shopping, meal preparation, delivery, house cleaning, gardening, taking care of other dependents, etc.)	FncImpAmntSpntPDCreMvng
		Expenses on home purchase or modifications (e.g., building a ramp in place of steps to enter/exit home)	FncImpAmntSpntPDCreVhcl
		Expenses to hire someone (e.g. a professional, relative, or friend) to provide daily non-medical care	FncImpAmntSpntPDCreHrSmnDlyCr
		Expenses related to financial and legal planning	FncImpAmntSpntPDCreHrSmnChrs
		One-time costs incurred for moving or purchasing a residence necessary to meet care needs (e.g., moving company fees, closing costs to purchase an accessible home)	FncImpAmntSpntPDCreTrnsprtn
			FncImpAmntSpntPDCreFncLgl

Cost Component	Equation using survey responses and derived variables	Variable	Fox Insight Variable Name
		Expenses related to care partner's respite care, defined as a short-term break given to the care partner to rest, travel, or spend time with other family and friends for a few hours to several weeks at a time. Respite care can take place inside or outside the home, including in a health care facility, or at an adult day care center.	FncImpAmntSpntPDCreRspte
		Increased transportation costs (e.g. driving, taking taxis or rideshares to and from clinics, rehab facilities, visiting PWPDP who live in nursing home, etc.)	FncImpAmntMnyAdltDayCre

Appendix E. Premature Death and Future Earnings Loss Calculations

Estimating Deaths Attributable to PD or AP

We employed two approaches to estimate the number of premature deaths associated with PD and AP in 2024. First, we used CDC-WONDER multiple cause of death files to identify deaths with and without PD indicated as cause of death. Deaths with ICD-10 G20 indicated as underlying cause of death were captured and all other deaths were attributed to the population without PD. While CDC WONDER is the national data source for deaths, it is not ideal for deaths associated with certain conditions, such as PD. Death certificates often underreport PD because it is often a secondary cause of death. In addition, CDC WONDER does not have granularity to identify the AP diagnoses of interest. Therefore, we supplemented these mortality data with death rates captured from the Medicare SAF 5%. In the Medicare data, we estimated death rates among beneficiaries ages 65 and older with at least one month of Part A and Part B coverage in the service year (2022, 2023). We estimated death rates in those with each of the PD and AP diagnoses of interest and in the comparison group.

For individuals under 65 years of age with PD, we estimated death rates based on both sources as follows:

- 1) In the Medicare 5% data, calculate PD, AP and non-PD death rates for each age year 65, 66, 67, ... through 74
- 2) Then, in the Medicare 5% data calculate PD/non-PD death ratio for each age year from Step 1 (do same for AP).
- 3) Next, we conducted a regression using PD/non-PD ratio from the Medicare 5% data as the Y and each age year (65, 66, 67, ... through 74) as the X. The coefficient is the average change in death ratio with each older year (do same for AP).
- 4) In CDC WONDER, we calculated PD and non-PD death rates for each age year (18, 19, 20, ... through 64)
- 5) Then, using CDC WONDER data we calculated PD/non-PD death ratio for each year (18 through 64)
- 6) Both Medicare and CDC WONDER : Applied the coefficient from Step 3 above to the ratios in Step 5 (for PD, not applicable for AP).
- 7) Applied this equation: PD death rate for each age (18 through 64) = CDC WONDER non-PD death rate (from Step 4) * "Adjusted" CDC-WONDER PD/non-PD death ratio (from Step 6)
- 8) Calculated the difference in death rates for PD and non-PD, and AP and non-AP for each age
- 9) Calculated excess death in each age year as the difference in death rate between PD and non-PD (from Step 8) * PD population (do same for AP)
- 10) Summed the excess rate for each age group of interest (18-49, 50-64, 65-74) for PD and for AP separately

After calculating the difference in death rates for the PD and non-PD populations for each age, we multiplied the difference by size of the weighted PD population for the age to calculate the number of premature deaths attributed to the disease (do same for AP).

Estimation of the Net Present Value (NPV) of Productivity Loss

The NPV of future earnings was calculated as follows:

Calculation of earnings loss was based on information about annual earnings adjusted for employment rate and mortality by age-gender strata using publicly available statistics for the US population. 2024 earnings and employment rates for the US population by age-group were obtained from the Bureau of Labor

Statistics. We were unable to incorporate specific PD or AP information on earnings and employment due to lack of available data.

- 1) Calculated the present value (PV) of future earnings for each year following death for ages 18-74 (by gender), adjusting for:
 - Survival rates from the CDC National Vital Statistics Report
 - Employment rates for the US population (by age-group and gender strata) in 2024 from the Bureau of Labor Statistics
 - Productivity growth (1%)
 - Discount factor (3%).
- 2) The estimated value of PV for future earnings was summed across each year to determine the total earnings loss based on each possible year of death (e.g., for someone who dies at age 72, PV of future earnings will be totals for future earnings at age 72, 73, and 74).
- 3) The average NPV of future earnings for each age-group was multiplied by the value of the number of premature deaths within each age-group to derive the estimate earnings loss from premature death due to diagnosis (PD or AP).

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

	CDC WONDER		Medicare Claims	
	PD Death Rate*	Non-PD Death Rate	Death Rate in PD Population^	Death Rate in Non-PD Population
Males				
18-49 years	0.0%	0.3%	2.0%	1.6%
50-64 years	0.7%	1.0%	7.1%	3.8%
65-74 years	2.8%	2.3%	6.8%	2.6%
≥75 years	12.4%	9.7%	18.0%	8.3%
Females				
18-49 years	0.0%	0.1%	0.0%	1.4%
50-64 years	0.6%	0.6%	5.3%	2.8%
65-74 years	3.4%	1.5%	5.9%	1.7%
≥75 years	9.7%	9.4%	15.6%	7.5%

Source: Lewin analyses of 2022-2023 CDC Wonder and 2023 Medicare 5% claims data.

*Deaths from CDC WONDER Multiple Cause of Death files 2022-2023 with PD as cause of death

^All-cause deaths among population with PD diagnosis in Medicare claims 2022-2023

Appendix F. Supplemental Results (Landscape)**Exhibit F 1. Estimated Size of Atypical Parkinsonism Population in the U.S. in 2024**

	U.S. Population	DLB		MSA		PSP		CBD/S		VP		AP NOS	
		N	%	N	%	N	%	N	%	N	%	N	%
Age	264,974,545	66,816	0.00025	16,868	0.00006	12,516	0.00005	5,068	0.00002	4,669	0.00002	15,520	0.00006
≤49	141,792,556	1,347	0.00001	3,380	0.00002	0	0.00000	185	0.00000	0	0.00000	185	0.00000
50-64	61,660,017	6,964	0.00011	4,022	0.00007	1,929	0.00003	1,290	0.00002	639	0.00001	3,405	0.00006
65-74	35,223,309	19,064	0.00054	4,611	0.00013	5,605	0.00016	2,137	0.00006	659	0.00002	4,461	0.00013
≥75	26,298,663	39,441	0.00150	4,855	0.00018	4,982	0.00019	1,456	0.00006	3,372	0.00013	7,469	0.00028
Sex													
Male	130,227,394	37,345	0.00029	9,467	0.00007	7,614	0.00006	1,768	0.00001	2,965	0.00002	8,809	0.00007
Female	134,747,151	29,471	0.00022	7,401	0.00005	4,902	0.00004	3,300	0.00002	1,705	0.00001	6,710	0.00005
Race/Ethnicity													
NH White	161,154,757	50,991	0.00032	11,352	0.00007	9,511	0.00006	4,110	0.00003	3,739	0.00002	12,364	0.00008
NH Black	31,955,514	11,192	0.00035	1,528	0.00005	2,401	0.00008	218	0.00001	685	0.00002	1,964	0.00006
Hispanic	47,303,971	1,985	0.00004	2,176	0.00005	370	0.00001	202	0.00000	135	0.00000	471	0.00001
Other	24,560,303	4,107	0.00017	196	0.00001	131	0.00001	33	0.00000	0	0.00000	1,740	0.00007
Insurance													
Private	138,862,094	1,070	0.00001	3,071	0.00002	599	0.00000	385	0.00000	119	0.00000	1,136	0.00001
Medicare	73,280,221	64,210	0.00088	12,667	0.00017	11,353	0.00015	4,491	0.00006	4,414	0.00006	13,956	0.00019
Medicaid	28,432,466	1,209	0.00004	732	0.00003	325	0.00001	103	0.00000	102	0.00000	135	0.00000
Other	24,399,765	327	0.00001	397	0.00002	239	0.00001	88	0.00000	35	0.00000	292	0.00001

Source: Lewin analyses of 2021-2024 Optum dNHI administrative claims, 2022-2023 Medicare SAF 5%, 2021-2022 Medicaid T-MSIS combined with 2023 Medical Expenditure Panel Survey (MEPS), 2022 Medicare Current Beneficiary Survey (MCBS), and Census population projection for 2024.

DLB is dementia with Lewy bodies; MSA is multiple system atrophy; PSP is progressive supranuclear palsy; CBD/S is corticobasal degeneration/syndrome; VP is vascular parkinsonism; AP NOS is parkinsonism not otherwise specified as indicated by ICD-10 G20.C.

*Other includes other insurance not listed above such as Indian Health Services.

Exhibit F 2. Average Per Capita Medical Costs* Incurred by Payer and Type of Service

Costs Incurred	Mean PWPDP/AP	Mean PWPDP Private	Mean PWPDP Medicare	Mean PWPDP Medicaid	Mean PWPDP Other^	Mean Comparison	Mean Comparison Private	Mean comparison Medicare	Mean comparison Medicaid	Mean comparison Other^
Non-acute institutional care	\$10,608	\$764	\$11,685	\$17,099	\$615	\$2,313	\$29	\$2,658	\$453	\$24
Hospital Inpatient	\$9,343	\$7,205	\$9,759	\$2,850	\$4,560	\$4,236	\$2,380	\$4,566	\$481	\$1,626

Costs Incurred	Mean PWP/AP	Mean PWP Private	Mean PWP Medicare	Mean PWP Medicaid	Mean PWP Other^	Mean Comparison	Mean Comparison Private	Mean comparison Medicare	Mean comparison Medicaid	Mean comparison Other^
Hospital Outpatient	\$5,332	\$9,153	\$4,987	\$1,632	\$6,170	\$3,820	\$4,821	\$3,792	\$152	\$3,689
Physician Office /Ambulatory Care	\$8,191	\$5,513	\$8,375	\$16,180	\$3,176	\$4,803	\$2,571	\$5,185	\$1,359	\$1,960
Durable Medical Equipment	\$731	\$170	\$812	\$316	\$124	\$484	\$33	\$555	\$17	\$24
Prescription Medication	\$4,202	\$2,729	\$4,416	\$3,854	\$1,808	\$3,464	\$2,578	\$3,667	\$527	\$1,980
Total cost	\$38,301	\$25,534	\$40,034	\$41,931	\$16,453	\$19,077	\$12,411	\$20,423	\$2,989	\$9,303

Lewin analysis of 2024 Optum claims, 2023 Medicare Standard Analytical File 5% sample claims, 2022 Medicaid T-MSIS data, and 2022 Medicare Current Beneficiary Survey (MCBS). PWP is Person with Parkinson's disease inclusive of atypical parkinsonism. Non-acute institutional care includes long-term and post-acute care, skilled nursing facility, rehabilitation facility, and hospice. Outpatient includes emergency department, urgent care, end-stage renal disease treatment facility, and ambulance. Office visits include physician office visits, ambulatory surgery, telehealth, physical therapy, occupational therapy, home-based care, laboratory facility, and other unlisted facilities.

*CPI adjusted to 2024 USD

^Other includes other insurance plans and uninsured.

Exhibit F 3. Non-Medical Costs Due to Parkinson's and Atypical Parkinsonism in 2024, by Age and Gender

	Total PWP/AP Population	Home Modification Cost		Motor Vehicle Related Cost		Increased Transportation Costs		Paid Household Help		Legal and Financial Planning		Respite Care	
		% of with Expense	Average Expense (\$)	% of with Expense	Average Expense (\$)	% of with Expense	Average Expense (\$)	% of with Expense	Average Expense (\$)	% of with Expense	Average Expense (\$)	% of with Expense	Average Expense (\$)
Males													
18-49 years	36,359	9%	\$1,567	14%	\$400	20%	\$1,471	23%	\$1,413	26%	\$3,698	6%	\$350
50-64 years	154,350	12%	\$8,277	8%	\$17,012	22%	\$230	23%	\$2,206	22%	\$2,209	6%	\$1,707
65-74 years	266,632	18%	\$6,050	8%	\$6,091	10%	\$559	11%	\$2,382	10%	\$2,453	5%	\$2,327
≥75 years	286,790	20%	\$12,952	10%	\$4,019	28%	\$355	32%	\$3,935	19%	\$5,204	8%	\$2,643
Females													
18-49 years	20,457	23%	\$7,501	19%	\$4,733	39%	\$1,170	44%	\$2,654	32%	\$4,380	9%	\$14,600
50-64 years	86,489	25%	\$11,354	12%	\$6,689	31%	\$394	36%	\$2,672	24%	\$2,218	7%	\$1,355
65-74 years	110,066	23%	\$11,220	10%	\$6,091	34%	\$379	37%	\$4,165	25%	\$2,714	5%	\$3,064
≥75 years	252,821	23%	\$10,531	13%	\$3,353	42%	\$811	46%	\$27,881	26%	\$2,794	5%	\$2,325
Overall	1,213,963	19%	\$9,996	10%	\$5,820	27%	\$557	30%	\$11,168	20%	\$3,238	6%	\$2,574

Source: Primary data collected through the 2024 PD Impact Survey, combined with PD and AP prevalence estimated by Lewin. PWP is Person with Parkinson's Disease inclusive of atypical parkinsonism.

Exhibit F 4. Other Out-of-Pocket Costs (not Covered by Insurance) Due to Parkinson's and Atypical Parkinsonism in 2024, by Age and Gender

	Total PWP/DP/AP Population	OTC & Supplements		Supplies		Medical Equipment		Activities		Counseling	
		% of with Expense	Average Expense (\$)	% of with Expense	Average Expense (\$)	% of with Expense	Average Expense (\$)	% of with Expense	Average Expense (\$)	% of with Expense	Average Expense (\$)
Males											
18-49 years	36,359	57%	\$1,223	20%	\$757	11%	\$45	54%	\$59	37%	\$3,704
50-64 years	154,350	69%	\$910	21%	\$664	22%	\$54	60%	\$175	28%	\$1,181
65-74 years	266,632	33%	\$885	10%	\$572	11%	\$30	29%	\$148	13%	\$1,143
≥75 years	286,790	64%	\$3,262	33%	\$707	33%	\$144	56%	\$238	18%	\$5,984
Females											
18-49 years	20,457	73%	\$828	47%	\$950	43%	\$262	58%	\$716	43%	\$1,058
50-64 years	86,489	83%	\$1,000	34%	\$772	31%	\$150	70%	\$279	33%	\$1,320
65-74 years	110,066	72%	\$899	32%	\$762	31%	\$1,169	59%	\$272	23%	\$2,073
≥75 years	252,821	72%	\$927	37%	\$519	40%	\$327	50%	\$461	19%	\$78,359
Overall	1,213,963	61%	\$1,505	27%	\$659	53%	\$238	51%	\$275	21%	\$16,684

Source: Primary data collected through the 2024 PD Impact Survey, combined with PD and AP prevalence estimated by Lewin. PWP/DP is Person with Parkinson's Disease inclusive of atypical parkinsonism.