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# 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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## 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 10th 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 *multiplying* 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 *multiplying* 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 neurodegenrerative 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 exspenses 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 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 exceding $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.

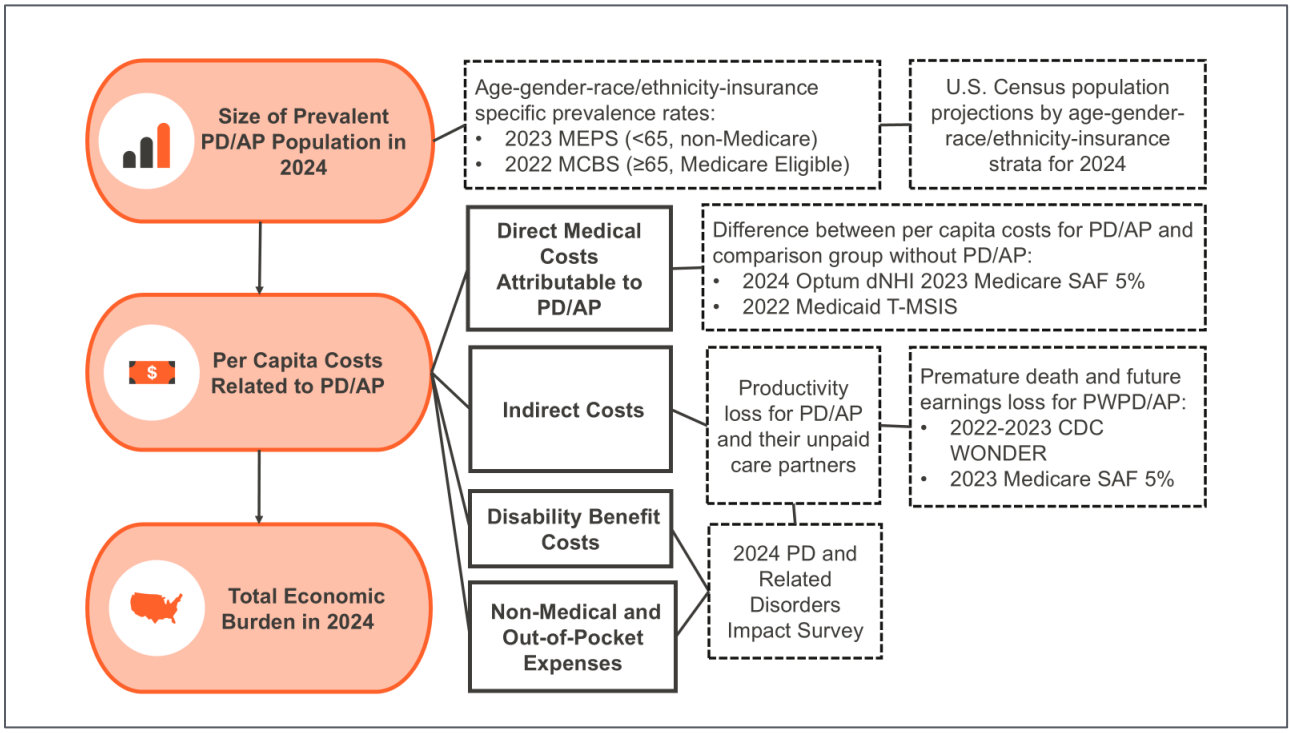
### Approach

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 PWPD/AP 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 PWPD/AP 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**



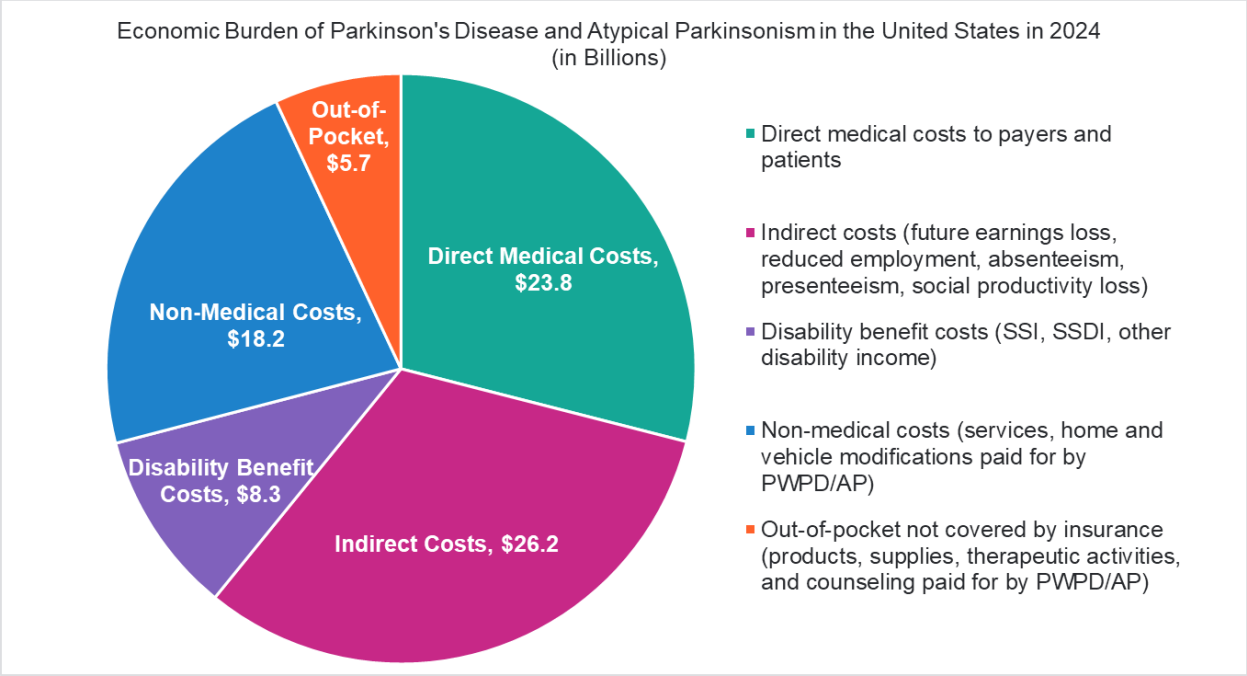

Abbreviations: PD Parkinson's Disease; AP Atypical Parkinsonism; dNHI Optum de-identified Normative Health Information; SAF Medicare Sample Analytic File; MCBS Medicare Current Beneficiary Survey; MEPS Medical Expenditure Survey; CDC Centers for Disease Control and Prevention; T-MSIS Transformed Medicaid 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 | | Per Capita Excess Medical Cost ($) |
|---|---|---|---|
| | (in Billion $) | Percentage of the Total | |
| **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 PWPD/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 PWPD/AP and care partners. We also include an estimated $8.3 billion in disability benefit costs for PWPD/AP. Per capita indirect costs for PWPD/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 $)^ | | | Per Capita ($) | | |
|---|---|---|---|---|---|---|
| | PWPD/AP Loss | Care Partner Loss | PWPD/AP & Care Partner | PWPD/AP Loss | Care Partner Loss | PWPD/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 PWPD/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 PWPD/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**

| | <65 | | | ≥65 |
|---|---|---|---|---|
| **Type of Service** | **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 PWPD/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 PWPD/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 |

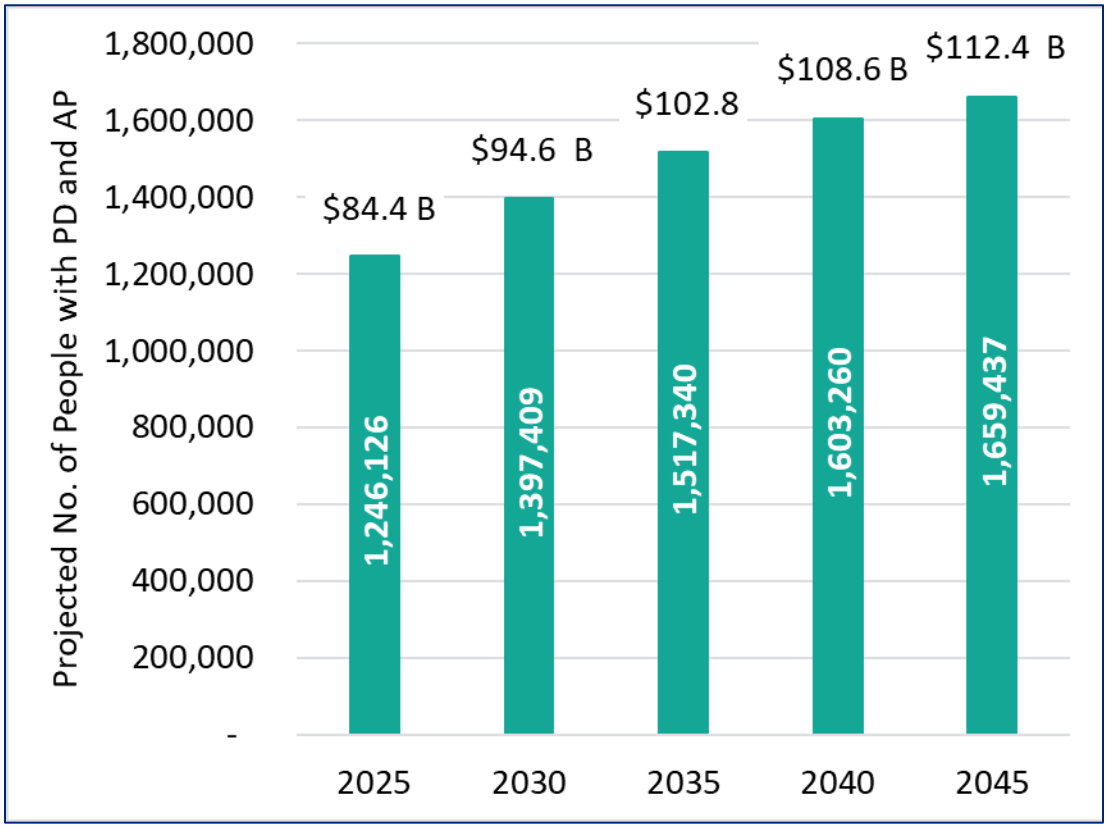
Lewin analysis of Optum dNHI administrative claims 2022-2024, Medicare SAF 5% 2022-2023, and Transformed Medicaid Statistical Information System (T-MSIS) 2022.

*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 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 and then $102.8 billion and $112.4billion 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 $82.2billion, including $23.8 billion in excess direct medical costs attributable to PD and AP and an additional $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. 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 PWPD/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^ | *Did not estimate economic burden* | |
| 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^† | *Did not estimate economic burden* | |
| 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^ | *Did not estimate economic burden* | |
| 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 PWPD/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 PWPD/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 PWPD/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;

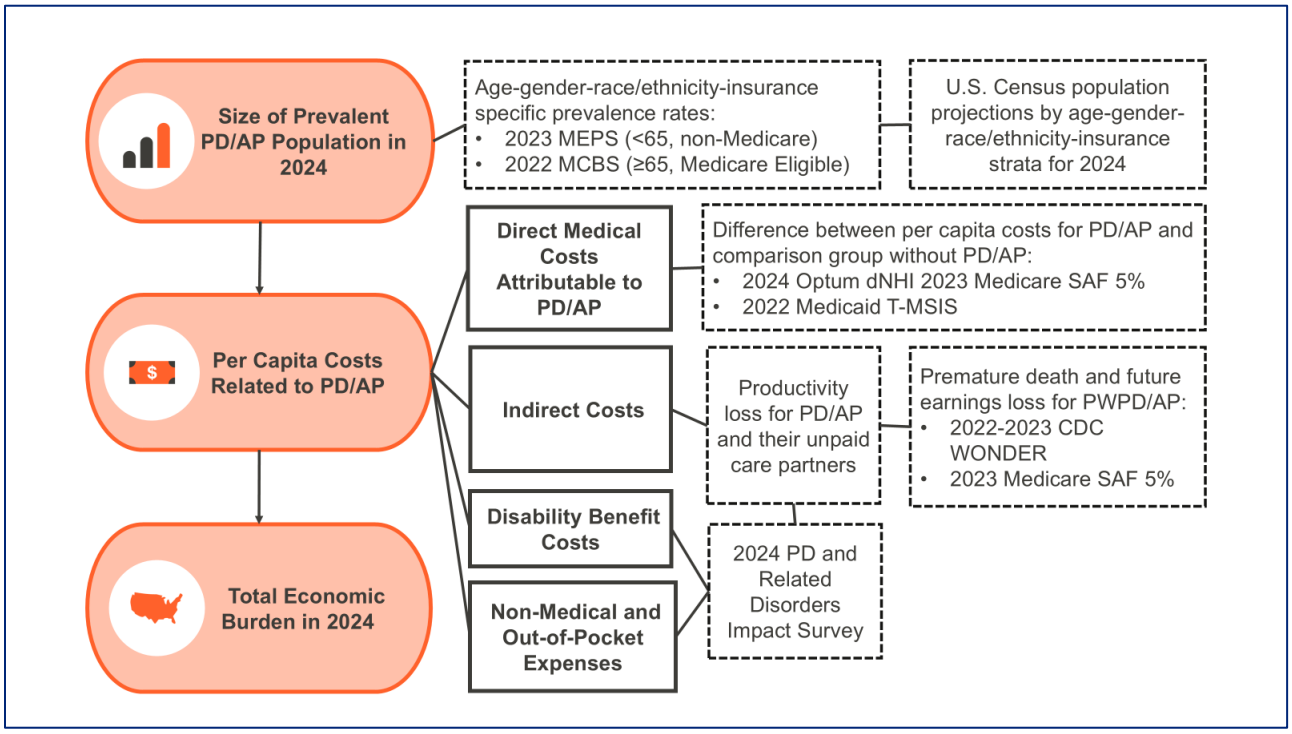
2) Estimate direct medical costs prior to formal diagnosis with PD or AP;
3) Estimate future economic burden; and
4) Describe the care partner experience.

## 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 PWPD/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[ɣ] 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
ɣOther 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**<br>(b) Active diagnosis in facility data **OR**<br>(c) Active diagnosis in long-term care data |
| MEPS | G20 | (a) Clinical Classification Software Refined (CCS) grouping for Parkinsonism **OR**<br>(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**<br>(b) 2 outpatient (OP) claims on separates dates of service **OR**<br>(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**<br>(b) 2 OP claims on separates dates of service OR<br>(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**<br>(b) 2 OP claims on separates dates of service |
| Multiple System Atrophy (MSA) | G23.2<br>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**<br>(b) 2 OP claims on separates dates of service |
| Vascular parkinsonism | G21.4 | (a) Dx on 1 IP claim **OR**<br>(b) 2 OP claims on separates dates of service |
| Parkinsonism not otherwise specified | G20.C | (a) Dx on 1 IP claim **OR**<br>(b) 2 OP claims on separates dates of service |

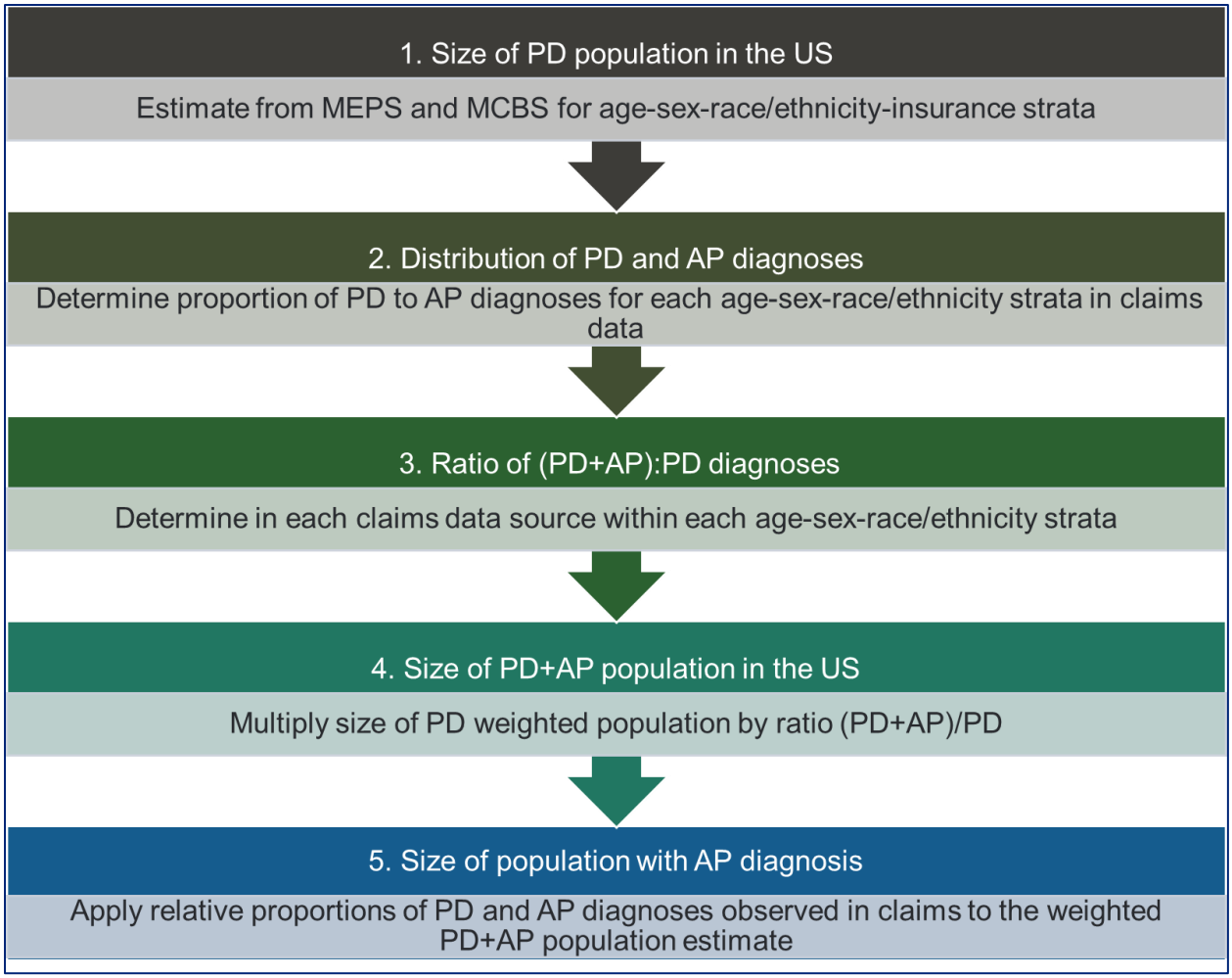
*Includes diagnosis codes that begin with these three digits.
^Drug lists in Appendix C. Code Lists

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:

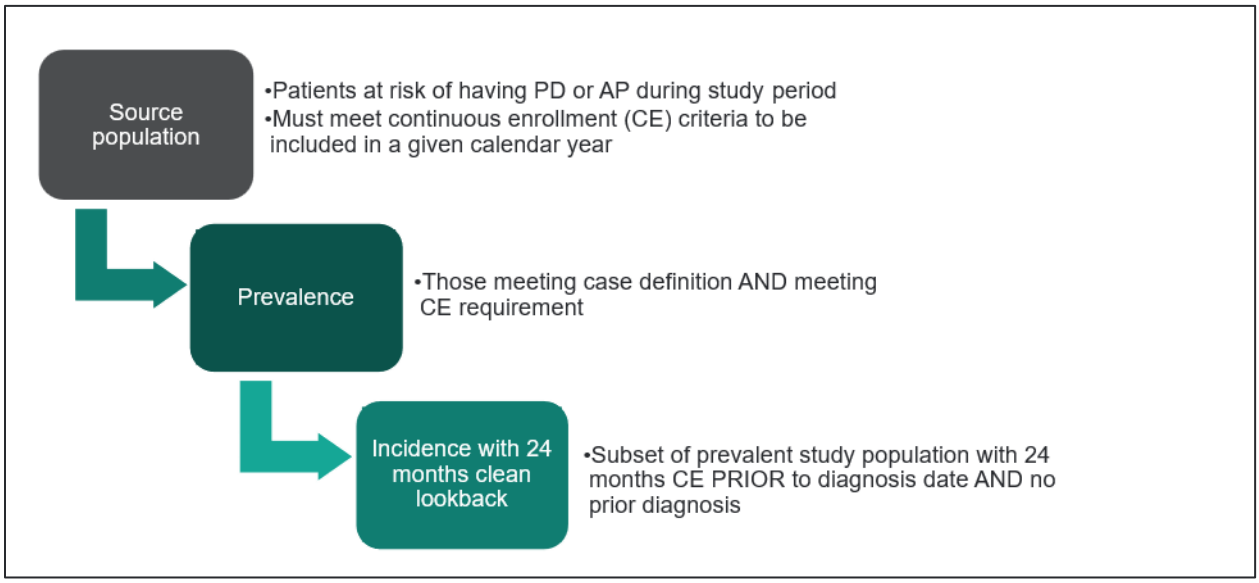
- Age group (18-49, 50-64, 65-74, ≥75)
- Gender (male, female)
- Insurance type (privately insured, Medicare, Medicaid, other)
- Race/ethnicity

### *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 *multiplied by* average number of months employed over past 12 months *multiplied by* 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 *multiplied by* average number of months employed over past 12 months *multiplied by* average daily earnings among those whose current job status is part-time or full-time *multiplied by* 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)) 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 PWPD/AP**

| Cost Component | Expense Paid for by PWPD/AP | 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 PWPD 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 dietician 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 PWPD/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 PWPD/AP. In addition, the new survey included questions about the physical, emotional, and financial impact of providing care for a PWPD/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.

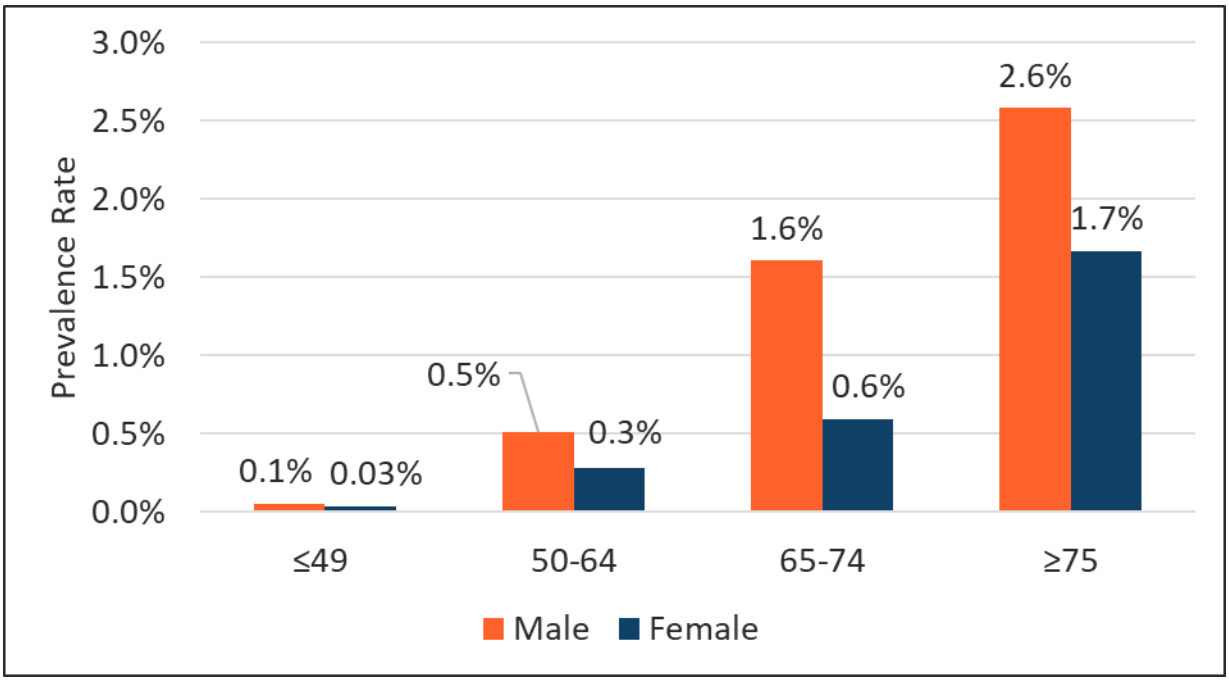
**Exhibit 11. Parkinson's Disease and Atypical Parkinsonism Prevalence by Population Characteristics**

| | 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**

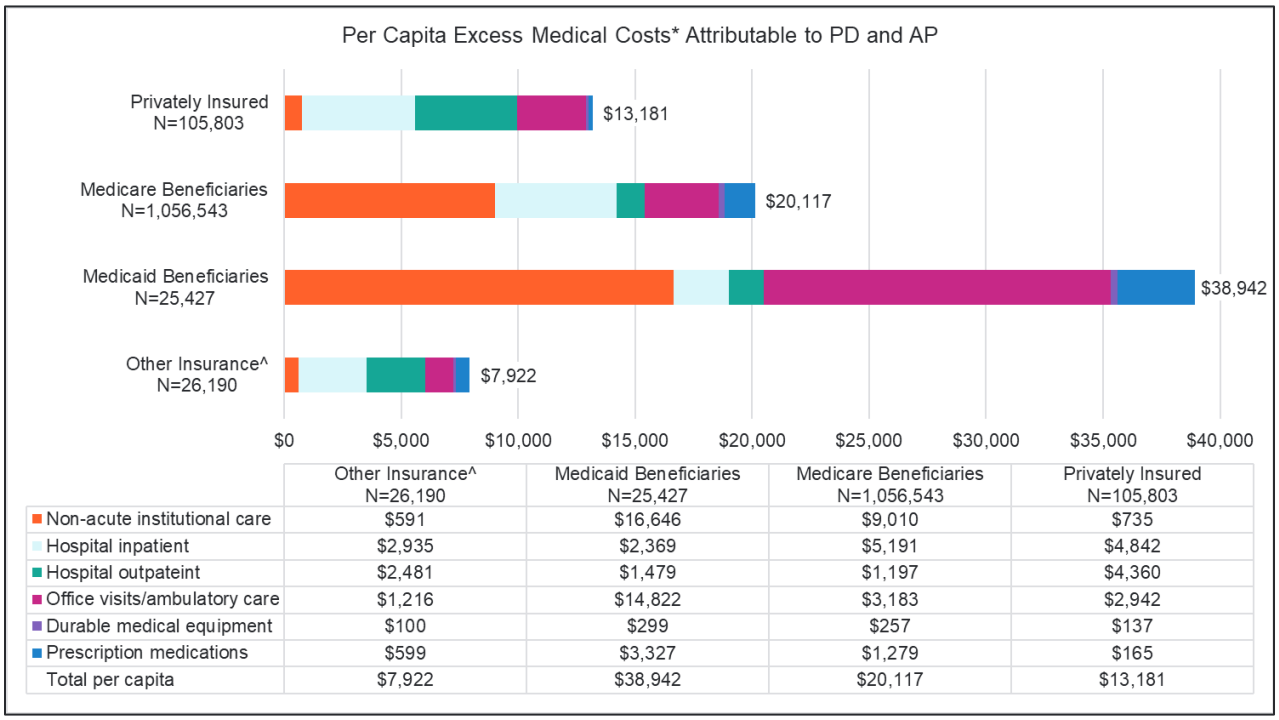
| Gender and Age Group | Total Excess Medical Cost* | | Per Capita Excess Cost due to PD or AP ($) |
|---|---|---|---|
| | Excess Cost (in Billion $) | Percentage of Total | |
| **Males** | | | |
| 18-49 years | $0.87 | 4% | $23,900 |
| 50-64 years | $3.40 | 14% | $22,050 |
| 65-74 years | $5.26 | 22% | $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 PWPD/AP 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 PWPD/AP 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**




| | Other Insurance^ N=26,190 | Medicaid Beneficiaries N=25,427 | Medicare Beneficiaries N=1,056,543 | Privately Insured N=105,803 |
|---|---|---|---|---|
| Non-acute institutional care | $591 | $16,646 | $9,010 | $735 |
| Hospital inpatient | $2,935 | $2,369 | $5,191 | $4,842 |
| Hospital outpateint | $2,481 | $1,479 | $1,197 | $4,360 |
| Office visits/ambulatory care | $1,216 | $14,822 | $3,183 | $2,942 |
| Durable medical equipment | $100 | $299 | $257 | $137 |
| Prescription medications | $599 | $3,327 | $1,279 | $165 |
| Total per capita | $7,922 | $38,942 | $20,117 | $13,181 |

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 PWPD/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 PWPD/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 PWPD/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 PWPD/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 | PWPD/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. PWPD/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, PWPD/AP under 65 years of age were less productive on more than 10 days per month on average. On average, PWPD/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 | 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 $)* |
| **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 | 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 $)^ |
| ≥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.
PWPD/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 PWPD/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 PWPD/AP in the past 12 months. Overall, 11% of PWPD/AP reported hiring someone to provide daily care or assistance in 2024 (Exhibit 24). In general, female PWPD/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 PWPD/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 PWPD/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. PWPD/AP is people with Parkinson's disease inclusive of atypical parkinsonism.

Exhibit 25 shows the percentage of PWPD/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 PWPD/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 |

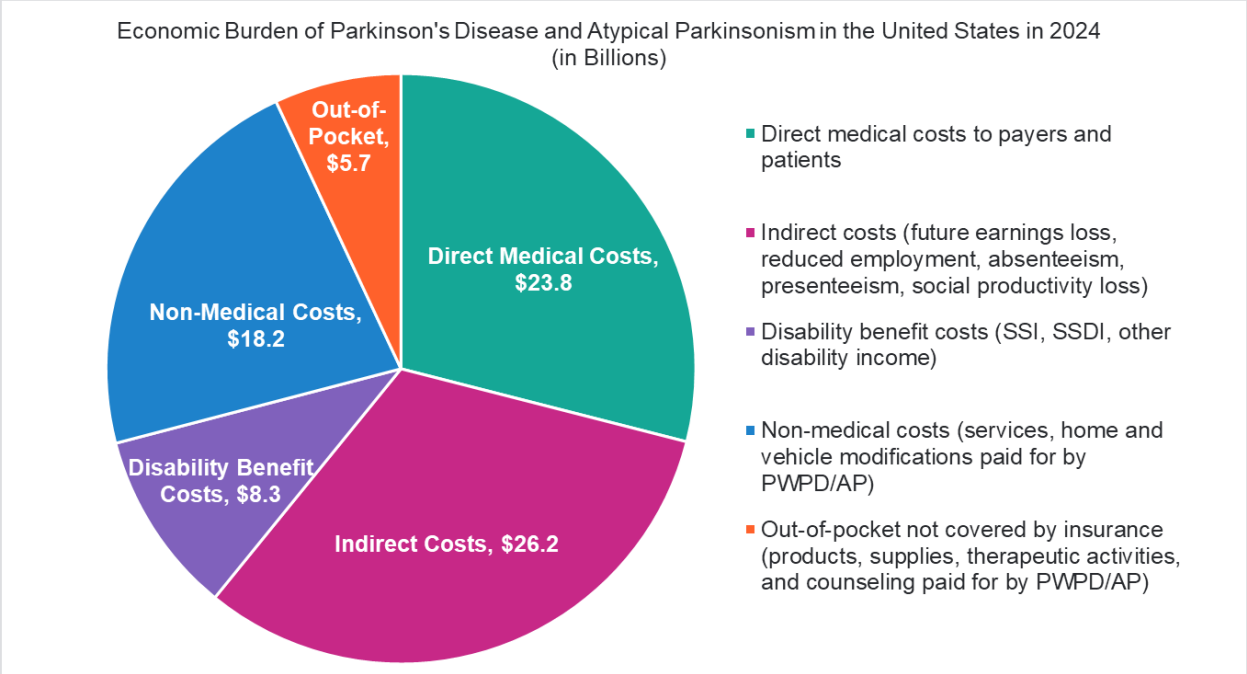
| Non-Medical Cost Component | % With Expense | Average Expense per User ($) | Total (in Billions $) |
|---|---|---|---|
| Home modifications | 19.3% | $9,996 | $2.34 |
| Motor vehicle modifications | 10.4% | $5,820 | $7.77 |
| Other increased transportation costs | 27.1% | $557 | $0.18 |
| Hiring someone 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* Attributable to PD or AP (in Billion $) | Percentage of the Total | Per Capita Excess Cost($) |
|---|---|---|---|
| ≥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 PWPD/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 PWPD/AP and care partners. We also include $8.3 billion in disability benefit costs for PWPD/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 $)^ | | | Per Capita ($) | | |
|---|---|---|---|---|---|---|
| | PWPD/AP Loss | Care Partner Loss | PWPD/AP & Care Partner | PWPD/AP Loss | Care Partner Loss | PWPD/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 | $5,5573 | $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 | 4,814 | 1,991,267 | 241.8 |
| Medicare | 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 |
|---|---|---|---|

*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 PWPD/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 PWPD/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 |

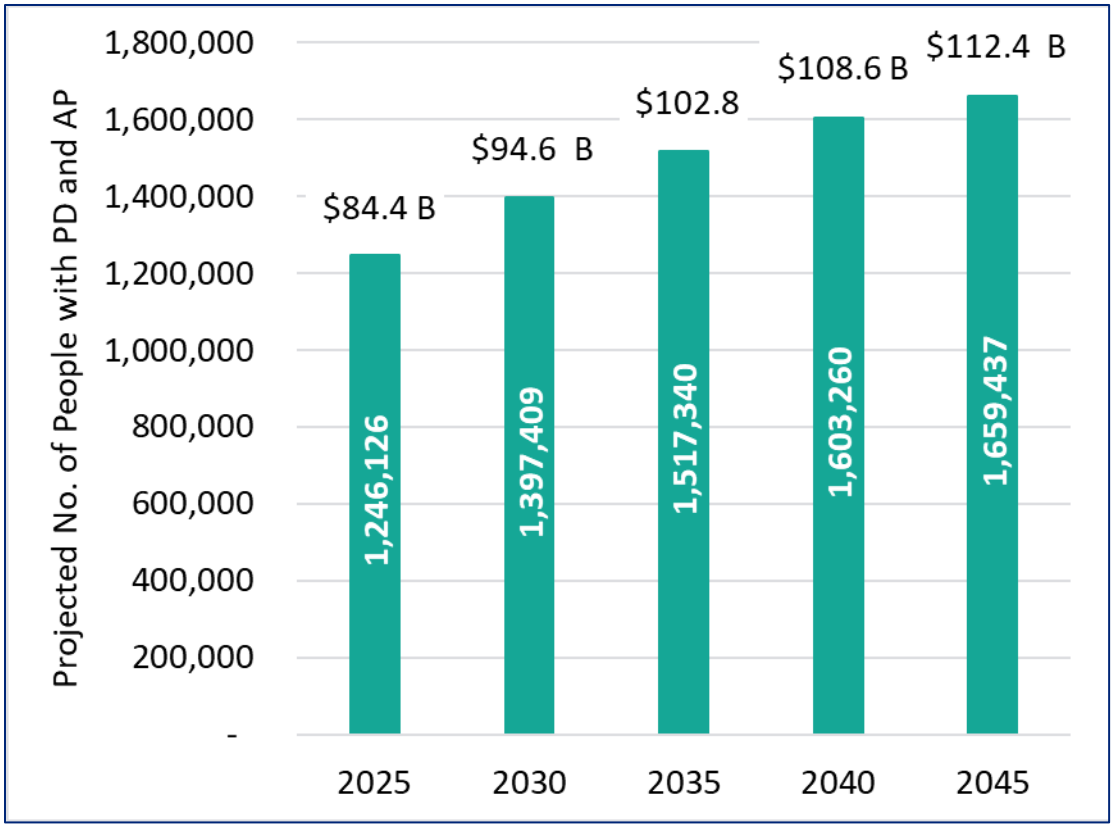
Lewin analysis of Optum dNHI administrative claims 2022-2024, Medicare SAF 5% 2022-2023, and Transformed Medicaid Statistical Information System (T-MSIS) 2022.
*CPI adjusted to 2024 USD.
^Cost ratio for average per capita medical costs prior to diagnosis relative to same age group and insurance type 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 PWPD/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 analysis of 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 PWPD/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**

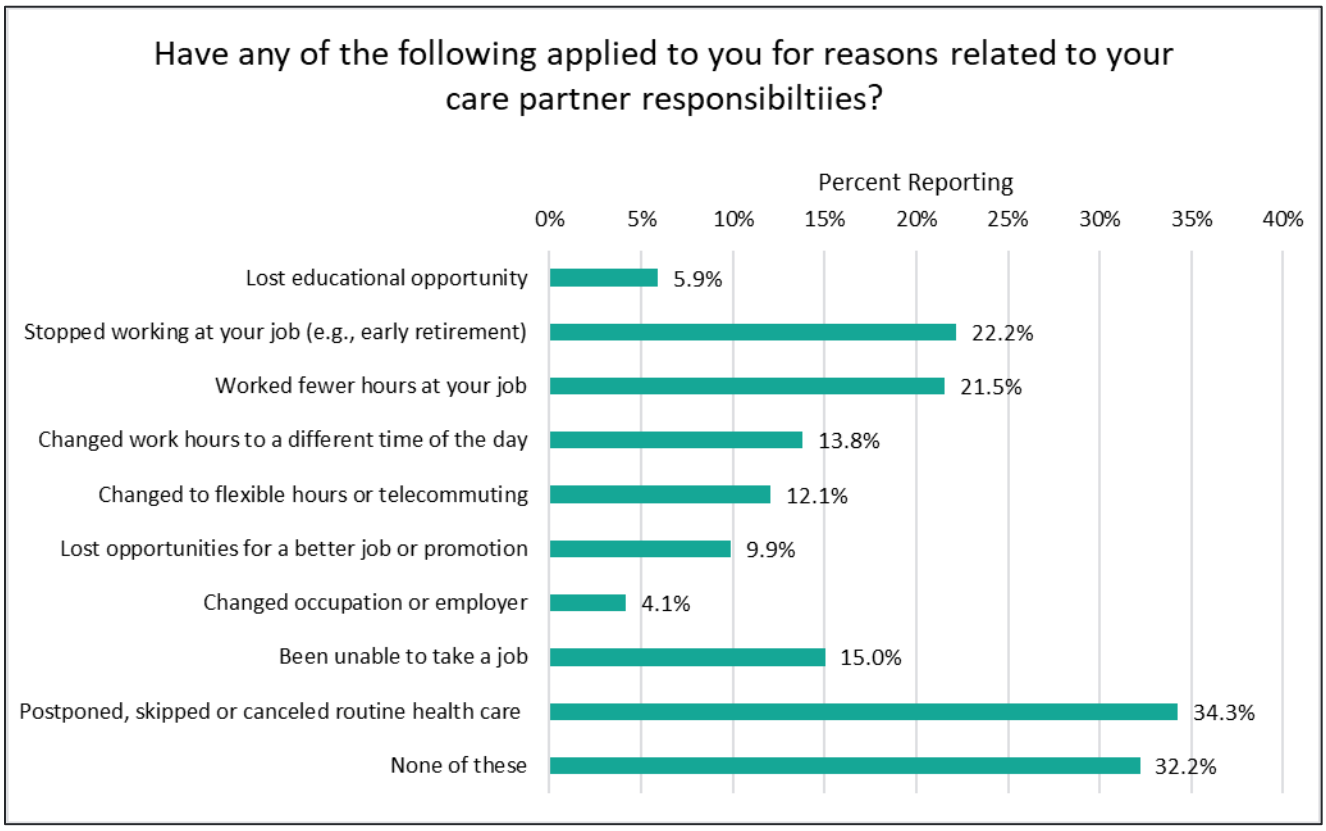
| Gender and Age Group | Survey Respondents | Number Receiving Unpaid Care | Percent Receiving Unpaid Care | Average Number of Unpaid Care Partners |
|---|---|---|---|---|
| **Males** | | | | |
| 18-49 years | 35 | 8 | 22.9% | 1.5 |
| 50-64 years | 440 | 134 | 30.5% | 2.1 |
| 65-74 years | 926 | 323 | 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).

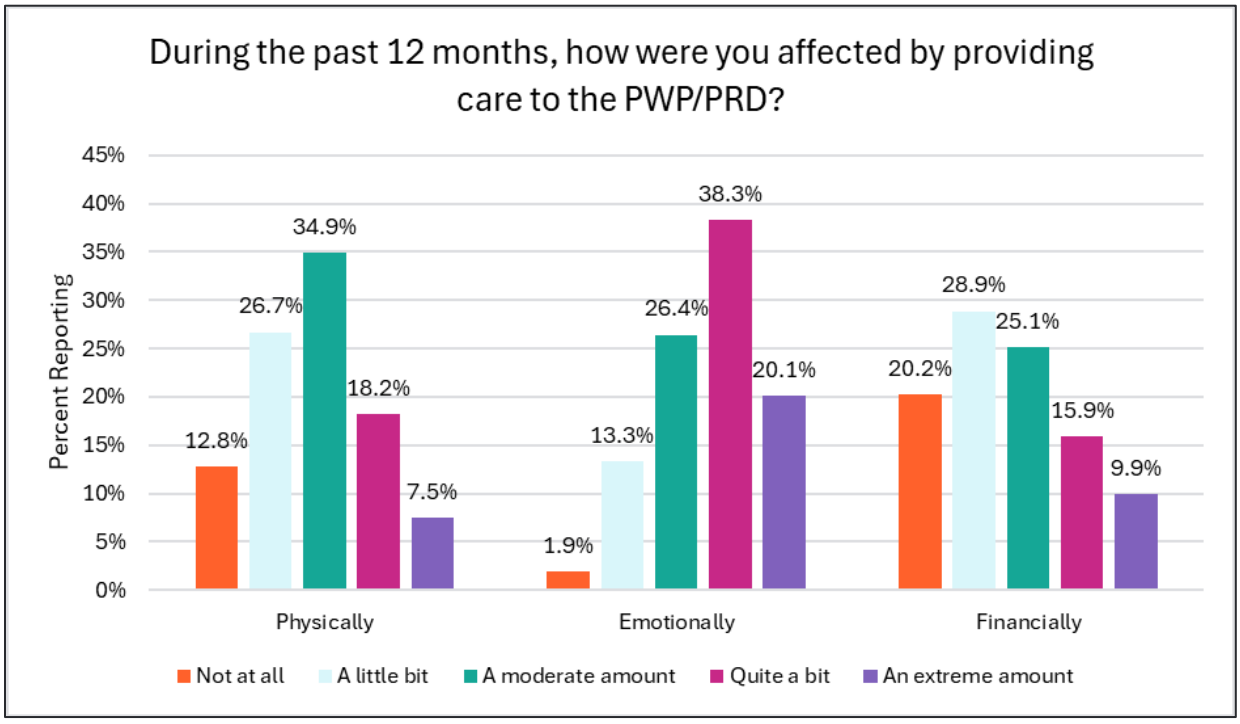
**Exhibit 35. Impact of Care Partner Responsibilities**




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 PWPD/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 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<br><br>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<br><br>Registry data | neurodegenerative diseases in medical record<br><br>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 PWPD in the U.S. in 2019 (based on 22,465 PWPD in the FI cohort) and found that PWPD 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 PWPD/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 PWPD/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 PWPD/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 PWPD 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 PWPD/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 PWPD/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 PWPD/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 PWPD/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 PWPD/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^ɣ<br>US Medicaid (2022)^ɣ<br>US Medicare (2022-2023)^ɣ | ICD-10 G20.*, G21.4, G23.1, G23.2, G31.85 | All ages<br><65<br>≥65 | 47.7<br>21.5<br>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) ^ɣ<br>Rochester Epidemiology Projectɣ<br>US Medicare (2012)ɣ<br>Ontario health administrative databaseɣ^ | Medical record review<br><br>ICD-9 332.* or ICD-10 G20.* | ≥65<br><br>≥65<br>≥65<br>≥65 | 125<br><br>108<br>212<br>185 |
| Savica et al, 2017 [53] | Rochester, MN all ages in 2005 | Rochester Epidemiology Project (1976-2005)ɣ medical records with clinical confirmation | Medical record review | All ages<br>0-39<br>40-59<br>60-69<br>70-79<br>80-99 | 17.2<br>0.1<br>9.2<br>55.1<br>119.2<br>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.
ɣRequired 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 PWPD/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 PWPD/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 PWPD/AP is greater. The National Alliance for Caregiving reported that care partners for PWPD/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 PWPD 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 PWPD/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 PWPD/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*

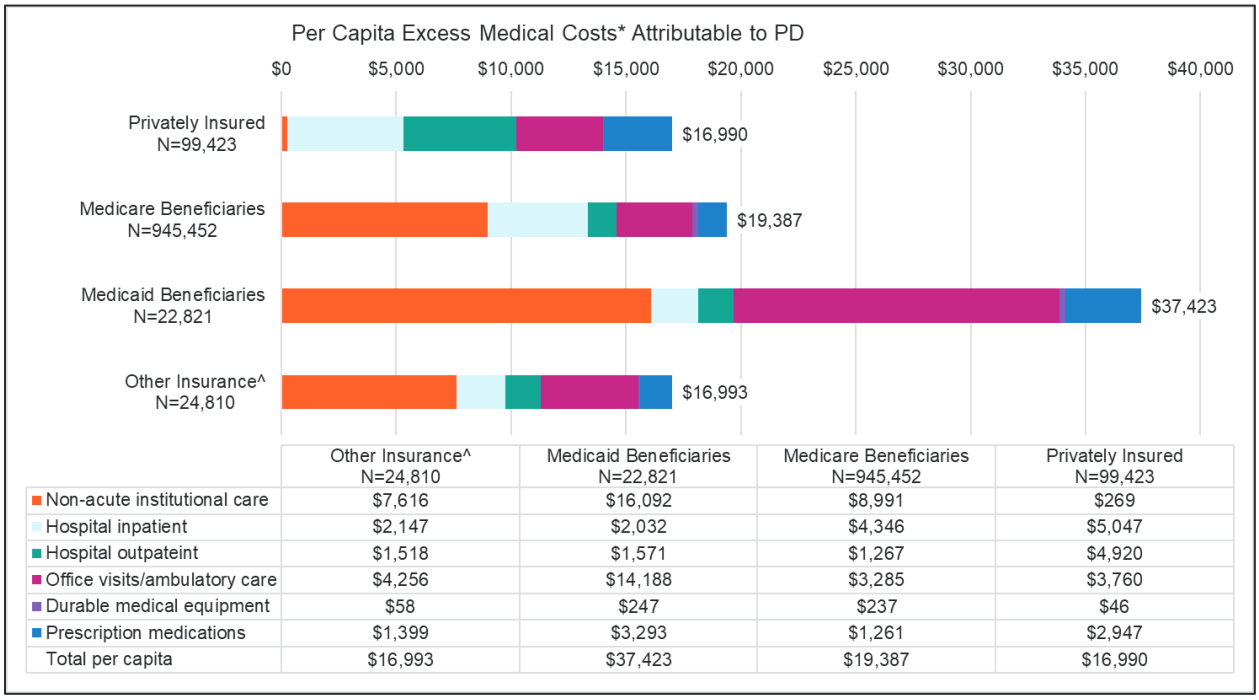
**Exhibit A 2. Direct Medical Cost of Parkinson's Disease by Age and Gender, 2024**

| | Total Excess Medical Cost*^ | | |
|---|---|---|---|
| | Excess Cost (in Million $) | Percentage of Total | Mean Excess Cost Attributable to PD ($) |
| **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*^ | | |
|---|---|---|---|
| | Excess Cost (in Million $) | Percentage of Total | Mean Excess Cost Attributable to PD ($) |
| 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**




| | Other Insurance^ N=24,810 | Medicaid Beneficiaries N=22,821 | Medicare Beneficiaries N=945,452 | Privately Insured N=99,423 |
|---|---|---|---|---|
| Non-acute institutional care | $7,616 | $16,092 | $8,991 | $269 |
| Hospital inpatient | $2,147 | $2,032 | $4,346 | $5,047 |
| Hospital outpateint | $1,518 | $1,571 | $1,267 | $4,920 |
| Office visits/ambulatory care | $4,256 | $14,188 | $3,285 | $3,760 |
| Durable medical equipment | $58 | $247 | $237 | $46 |
| Prescription medications | $1,399 | $3,293 | $1,261 | $2,947 |
| Total per capita | $16,993 | $37,423 | $19,387 | $16,990 |

*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¥ |
|---|---|---|---|---|
| **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.
¥Other 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 $)* |
|---|---|---|

Source: Primary daprta 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 PWPD 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 | | |
|---|---|---|---|
| | (in Million $) | Percentage of the Total[x] | Per Capita ($) |
| **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 $) | Percentage of the Total[ɣ] | Per Capita ($) |
| **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.
[ɣ]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 PWPD Loss^ | Per Capita PWPD 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 PWPD Loss^ | Per Capita PWPD 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 PWPD/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. PWPD 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% | NA8 | 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[ɣ] | $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.
[ɣ]Other 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**

| | N | % |
|---|---|---|
| **Respondent** | | |
| 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. PWPD 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

| | PWPD | | 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. PWPD is Person with Parkinson's Disease, PWAP is Person with Atypical Parkinsonism.

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

| | PWPD | | 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 PWPD, and excludes co-residents who are financially independent and all paid care partners who are not family members. PWPD is Person with Parkinson's Disease, PWAP is Person with Atypical Parkinsonism.

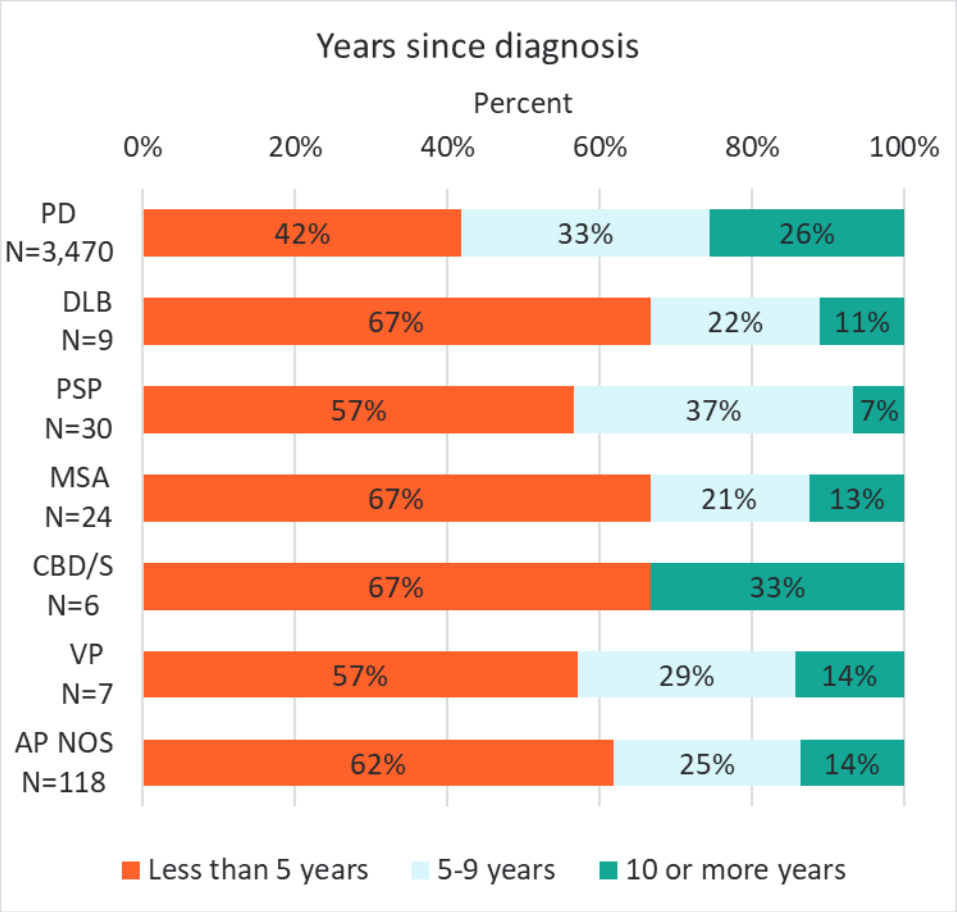
### Exhibit A 37. Veteran Status of Survey Sample

| | PWPD | | 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) |
| Benztropine (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 (Benztropine) |
| 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 Nouriast) |
| 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 Equfina) |
| 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<br>G25.2 |
| Speech impairment | R47 |
| Gait disorders | F26 |
| Constipation | K59 |
| Mood disorder | F30<br>F31<br>F32<br>F34<br>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 PWPD/AP or care partners** | ***Only applies to PWPD/AP or care partners who retired early or stopped working for reasons related to their disease:*** | Current job status = retired or not working | FnclImpJobStat |
| | | Disease played a role = yes | FnclImpWrkDcsn |
| | **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 age | Age_current |
| | | Age left workforce | FnclImpYrRtrd |
| | | Median annual earnings in 2024 from BLS | |
| **Reduced earnings** | ***Only applies to PWPD/AP or care partners who are still working:*** | Current job status = part or full-time | FnclImpJobStat |
| | **Absenteeism** = days missed in an average month * average number of months employed past year *average daily earnings | months employed past year | FnclImpMnthsEmplyd |
| | | Days missed work | FnclImpDaysMssdWrk |
| | **Presenteeism** = days less productive in an average month * average number of months employed past year * adjustment factor * average daily earnings | months employed past year | FnclImpMnthsEmplyd |
| | | Adjustment factor from earnings for PD and non-PD populations in MEPS | Derived from MEPS |
| | | Days felt less productive | FnclImpDaysLessPrdctve |
| | **Daily Earnings** = Annual earnings / months employed past year / 30.25 | months employed past year | FnclImpMnthsEmplyd |
| | | Annual earnings (using mid-point for each category) | FnclImpHsehldEarn |
| **Social productivity** | ***For individuals who are working:*** | Current job status = part or full-time | FnclImpJobStat |
| | **Social Productivity Loss =** (Hours affected [BEFORE hours – AFTER hours]) * average hourly income for age-gender stratum * value of leisure time * 52 | 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) | Before hours | SocProdBefore |
| | | After hours | SocProdAfter |
| | | Average hourly value placed on volunteering | From Independent Sector Report on Value of Volunteer Time |
| | *Backup question to provide the number of hours spent by care partners on providing care. | 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 | FnclImpDsbltyIncmeSSI<br>FnclImpDsbltyIncmeSSDI<br>FnclImpDsbltyIncmeOthr |
| | **Disability income** = SSI + SSDI + OTDI | Supplemental Security Income (SSI) | FnclImpDsbltyIncmeSSIAmnt |
| | | Social Security Disability Insurance (SSDI) | FnclImpDsbltyIncmeSSDIAmnt |
| | | Other types of disability income (OTDI) | FnclImpDsbltyIncmeOthrAmnt |
| **Out-of-pocket (OOP) costs (not covered by insurance)** | **Medical Care OOP (not covered by insurance)** = Prescriptions + Products + Supplies + DME + Activities + Counseling | Prescriptions | FnclImpAmntSpntAllPrscrptns |
| | | Products (OTC and supplements) | FnclImpAmntSpntProducts |
| | | Supplies (adaptive clothing, feeding equipment) | FnclImpAmntSpntSupplies |
| | | Durable medical equipment | FnclImpAmntSpntMedEqpmt |
| | | Activities (gym, exercise classes, online classes, home exercise equipment) | FnclImpAmntSpntActvts |

| Cost Component | Equation using survey responses and derived variables | Variable | Fox Insight Variable Name |
|---|---|---|---|
| | | Counseling (patient education, psychotherapy, nutrition counseling, dietician) for PWPD/AP and care partners | FnclImpAmntSpntCnslng |
| | ***Expenses related to facilities should be weighted by number of months spent in respective facility*** | Months in rehab facility | FnclImpAmntMnthsOutptRehFclty |
| | | Months in hospice | FnclImpAmntMnthsHspce |
| | | Months in nursing home | FnclImpAmntMnthsNrsngHme |
| | | Months in SNF | FnclImpAmntMnthsSklldNrsngFac |
| | | Months in other longterm care | FnclImpAmntMnthsOthr |
| | | Adult outpatient rehab facility expenses | FnclImpAmntMnyOutptRehFclty |
| | | Hospice facility expenses | Q28_4_1 |
| | | Nursing home expenses | FnclImpAmntMnyNrsngHme |
| | | Skilled nursing facility expenses | FnclImpAmntMnySklldNrsngFac |
| | | Other long term care expenses | FnclImpAmntMnyOthr |
| **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 | FnclImpAmntSpntPDCreHrSmnDlyCr |
| **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 | FnclImpAmntSpntPDCreHmeMod |

| 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.) | FnclImpAmntSpntPDCreMvng |
| | | Expenses on home purchase or modifications (e.g., building a ramp in place of steps to enter/exit home) | FnclImpAmntSpntPDCreVhcl |
| | | Expenses to hire someone (e.g. a professional, relative, or friend) to provide daily non-medical care | FnclImpAmntSpntPDCreHrSmnDlyCr |
| | | Expenses related to financial and legal planning | FnclImpAmntSpntPDCreHrSmnChrs |
| | | 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) | FnclImpAmntSpntPDCreTrnsprtn |
| | | | FnclImpAmntSpntPDCreFnclLgl |

| 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. | FnclImpAmntSpntPDCreRspte |
| | | Increased transportation costs (e.g. driving, taking taxis or rideshares to and from clinics, rehab facilities, visiting PWPD who live in nursing home, etc.) | FnclImpAmntMnyAdltDayCre |

# 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 deaths 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

| | | DLB | | MSA | | PSP | | CBD/S | | VP | | AP NOS | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | U.S. Population | 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 PWPD/AP | Mean PWPD Private | Mean PWPD Medicare | Mean PWPD Medicaid | Mean PWPD 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 PWPD/AP | Mean PWPD Private | Mean PWPD Medicare | Mean PWPD Medicaid | Mean PWPD 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

| | | Home Modification Cost | | Motor Vehicle Related Cost | | Increased Transportation Costs | | Paid Household Help | | Legal and Financial Planning | | Respite Care | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Total PWPD/AP Population | % 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. PWPD 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 PWPD/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. PWPD is Person with Parkinson's Disease inclusive of atypical parkinsonism.