Supporting Value-Based and Integrated Care Models for Parkinson's Disease

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INTRODUCTION

Parkinson's disease (PD) is a chronic, progressive condition of largely unknown cause that affects the nervous system and all innervated parts of the body. Despite the range of motor and non-motor-related symptoms that a patient with PD may experience, current treatment options are often limited to unimodal medical management interventions. The heterogeneity and complexity of individual circumstances for those living with PD necessitates more comprehensive approaches, including nonpharmacological measures such as physiotherapy and speech therapy, which focus on improving quality of life for individuals and their caregivers.

In this paper, the Duke-Margolis Institute for Health Policy describes a new model for PD care, services, and payment approaches that can be adjusted for different levels of infrastructure and resource capabilities. To more effectively manage symptoms and disease progression, greater flexibility is required to provide coordinated care and longitudinal management of PD. Accompanying payment components of the model are designed to support proactive and protracted care, flexible care delivery, and accountability for long-term outcomes. Our proposal reflects independent analysis of existing PD care models, semi-structured stakeholder interviews, and insights from an expert workshop.

BACKGROUND

Parkinson's disease is the second most common neurodegenerative disorder, with approximately 90,000 people in the U.S. diagnosed with PD each year.[1] The incidence of PD increases with age, the incidence of PD in the U.S. has increased overall, making the Medicare population particularly vulnerable.[2] The prevalence of PD has nearly doubled since 1978,[3] indicating a greater burden on the health care system, caregivers, and payers at a time when already physician shortages exist, particularly with specialists such as neurologists.[4] The underlying cause of the disease remains unknown, though experts currently believe it is caused by a combination of environmental and genetic factors.[5] No cure for PD exists,[6] though medications and medical services can manage symptoms.

Living with Parkinson's Disease

Diagnosis of PD is based on patient history and physical examination.[7] Certain imaging scans, such as an MRI of the brain or a dopamine transporter scan, can support diagnosis or rule out similar conditions, but no single test confirms PD. Thus, formal diagnosis can sometimes take months or years, which can in turn lead to missed opportunities for earlier-stage disease planning and interventions. The recent identification of alpha-synuclein as a biomarker may lead to earlier and more accurate diagnoses in the future.

Symptoms for PD vary from person to person and may include a range of motor and non-motor-related symptoms. Clinical presentation has historically focused on the presentation of motor symptoms. In more recent years, recognition of the non-motor symptoms has increased. PD symptoms span the whole body and can greatly affect quality of life.[8]

Pharmacologic interventions can help with symptom management to maintain patient quality of life.[9] Certain medications can improve day-to-day motor function in patients, including carbidopa-levodopa (CD/LD), which has been the standard for reducing tremors and other motor symptoms for nearly fifty years.[10] Effectiveness of CD/LD decreases over time as the disease progresses, and patients may require higher doses and additional medications to manage "off" periods, during which symptoms become more noticeable.[11] Effective management of symptoms can be transformative for patients, and many medications have generic options. Yet, pharmacologic interventions have side effects (such as issues with impulse control), or can require prior authorization for payer coverage. In recent years, researchers have studied disease-modifying therapies for neurodegenerative conditions and increased focus on identifying biomarkers and working towards disease-modifying therapies for PD, although none currently exist on the market.

Forms of physiotherapy are the most common types of non-pharmacologic interventions. High-intensity exercise has shown promise for delaying PD progression and helping patients maintain motor function in early disease stages. Different types of exercise have different impacts on patient motor symptoms and quality of life. Dance may have moderate effects on motor symptoms, and water-based exercise may improve patient-reported quality of life.[12] Aerobic, high-intensity exercise in early disease stages is currently being studied for its promising potential to delay disease progression.[13] Combining aerobic exercise with other types of physiotherapies and exercise regimens may help maintain motor function.[14] While physiotherapy is a promising and emerging area of PD management, availability and access remain two key barriers to the uptake of exercise. Under the current fee-for-service (FFS) payment structure, insurers will often cover physical therapy but not these types of preventive physiotherapy options.

Current Costs and Payment for PD Care

Given its chronic and progressive nature, PD is a costly disease to manage. While little data exists on the total cost of care of PD and total patient out-of-pocket (OOP) costs, the five-year incremental cost of PD to Medicare has been estimated at around $27,466 per patient.[15] This number does not account for disease progression costs. PD management becomes progressively costlier as patients need additional medications, durable medical equipment, respite services, and procedures. Additionally, patient access to exercise interventions at early disease stages may depend on patient distance to a gym, availability of staff with PD knowledge or staff that can interpret physician recommendations or prescriptions for exercise, or cost of membership. Many insurers, such as Medicare, cover most services and medications for PD care. However, the accumulation of co-pays, coinsurance, drug costs, and services that are not covered by insurance (such as some types of home care, exercise courses, or modifications to the home that make mobility easier) can make costs prohibitive for patients and caregivers over time.

An estimated 90 percent of individuals with PD are eligible for Medicare. Close to 40 percent are estimated to have Medicare Advantage (MA), and 60 percent have traditional FFS Medicare.[16] The number of individuals with PD who are eligible for both Medicare and Medicaid ranges from around 10 percent to over 25 percent depending on the state. Medicare patients with PD tend to have higher rates of inpatient and emergency department (ED) admissions, rehabilitation visits, and non-PD medication fills than those without PD, contributing to high costs.[17] In the FFS system, payments are linked to the volume of health care services. Consequently, the FFS system does not encourage high-value activities that support patient health, such as investments in health information technologies, certain care coordination functions, or increasing access to care outside of traditional health care settings.[18] The FFS system does not incentivize proactive preventive care, particularly for chronic conditions.[19]

Value-based payment models, where payments are based on outcomes or other measures of value, can offer providers more flexibility in the care they provide for patients. For example, payment models that include financial incentives for better outcomes can provide incentives to address the aforementioned issues to improve outcomes. Other payment models can offer reimbursements or flat fees that can cover services that are not typically reimbursed, but may lead to better patient outcomes and long-term cost savings. This can, in turn, help provide financial buffers in case of financial shocks. Commercial insurance payers and MA providers, in particular, have more flexibility in contracting and entering value-based payment models. The Centers for Medicare & Medicaid Services (CMS) have tools to test and create new payment models for certain populations or conditions through the Center for Medicare and Medicaid Innovation (CMMI) for Traditional Medicare beneficiaries.

Current Approaches to PD Care

Despite PD being a neurological disorder, fewer than half of PD Medicare beneficiaries see a neurologist, and fewer than 10 percent see a Movement Disorders Centers of Excellence (MDC), which serve as the most specialized places to receive care for PD.[21] Several barriers prevent individuals from accessing high-value care throughout disease progression. Education around differentiating PD symptoms from normal aging, geographic distance from providers, financial constraints, and specialist shortages all can contribute to delayed diagnoses.[22] The social stigma around having a mobility-related disorder contributes to why people may not access the appropriate specialist services.[23] Additionally, structural racism and unconscious biases within the health care system has led to racial disparities in PD diagnoses in the U.S. For example, Black patients are less likely to be diagnosed with PD than White patients—when controlling for age and education—and are more likely to be in a later stage of disease progression when diagnosed.[24] Disparities in the geographic distribution of health care resources also impact patient access to high-quality care. MDCs are limited in quantity and operational capacity. Patients may have to travel far distances to reach this type of specialty care, or even if patients are close to an MDC, they may lack access based on their insurance status.[25] Further, studies have shown that patients don't feel like they can access PD-related health care services as frequently as they would prefer.[26]

As PD is a whole-body condition that spans multiple systems, effective management of the disease necessitates a multidisciplinary team approach.[27] However, the current landscape of PD care is complex, fragmented, and inconsistent. Patients may have their PD-related care managed by a neurologist, movement disorder specialist (MDS), primary care physician (PCP), or a combination of the three. Beyond their primary physician, many other providers support a patient's PD care based on their symptoms. From our patient interviews and research, most patients noted having to coordinate their own care and appointments with various specialists.

A few existing PD care models are designed to increase coordinated patient care. This paper highlights seven PD-specific care models in the U.S. and globally, including three clinical trial-based models (**Table 1; Table 2**). While this is not an exhaustive list, these models exemplify multiple approaches to PD care, including those in MDCs, some that utilize home care, and others that include telehealth interventions. These models also include innovations that could be incorporated into future versions. The care settings, providers included, types of non-medical care included, and payment approaches vary.

While the specifics of each model vary, they share some common components. Each includes multidisciplinary care teams and nearly all include a care coordination role, though who took on that role varied. The ParkinsonNet and PRIME models utilize IT platforms to enable communication between patients and their care teams. Notably, these models focused on personalized care, including creating care plans and goals with multiple providers, tracking progress and outcomes through journals, and meeting patients in different settings.

These current models impact care delivery for specific, local subsets of the PD population. For example, ParkinsonNet has improved quality-of-care outcome measures and reduced costs, though this model was designed around a small geographical region in the Netherlands. The University of North Carolina (UNC) half-day clinic allows

Table 1 | PD Care Models

Model	Description
UNC Interdisciplinary Parkinson's Disease Clinic	This is a half-day clinic that provides a one-time consultation from five clinicians. The five clinicians include a movement disorders specialist/neurologist, a clinical social worker, a physical therapist, an occupational therapist, and a speech therapist.[28]
Proactive and Integrated Management and Empowerment in Parkinson's Disease (PRIME)	The PRIME Parkinson model leveraged existing infrastructure to deliver personalized care by a multidisciplinary team in the UK and the Netherlands.[29]
ParkinsonNet	ParkinsonNet is a network-based model which began in the Netherlands and now has partners in multiple countries. This model includes access to regional multidisciplinary networks of health professionals, community-based therapists, and specialist care in hospitals, nursing home care, and facilitated by an IT platform.[30]
Struthers Parkinson's Clinic	The Struthers Parkinson's Clinic is a free-standing center with five neurologists and on-site PT, OT, speech, music therapy, social work, and skilled PD-experienced nurses.[31]

patients to meet with a set of providers for evaluations and goal setting and may be more appropriate for patients in the early stages, newly diagnosed patients, or those who want to set care goals. The UNC clinic does not provide longitudinal care and has limited availability. While these models have been shown to lower costs and improve outcomes or patient satisfaction, they have limited geographic reach, appointment availability, and applicability to the wider U.S. context.

The PD clinical trial models identified (**Table 2**), were less comprehensive than the above care models, but tested innovative ways to monitor or bring care to patients.

- The CHAPS trial tested nurse-led, telephone-administered care for veterans in the southeastern U.S., which led to patients highly rating medication self-management and knowledge of PD, and rating care managers as helpful. However, they noted some challenges with the provided self-care tools. Nurses in the program reported the CHAPS Assessment and Program helped them facilitate care for individuals with PD.[32]
- One trial in the UK used watches to remind patients to take medications and gather data on patient motor symptoms and sleep disturbances as patients went about their day-to-day activities. Providers were able to look at the remote data and adjust medications and discuss symptoms with patients. This program is being expanded with government funding.[33]
- A non-randomized trial at Rush University tested whether home visits and telehealth programs could lead to better outcomes for homebound individuals with PD in the advanced stages of the disease. Nurses and care coordinators visit patients in their homes for an initial assessment, including a home safety assessment, followed by setting up telehealth support with specialists.[34] Patients in the home care program reported stable quality of life, improved bodily comfort, and increased communication with providers compared to the control group.[35]

Other models and proposed care models outside of PD also were examined for their potential innovations that could be applied to PD care. In particular, we focused on CMMI models and models for other neurodegenerative conditions, such as dementia. The new CMMI GUIDE model for dementia care, for example, offers respite care for caregivers.[38] A proposed dementia care model suggested increasing payments based on tiers determined by disease severity and social need.[39] ALS and Cystic Fibrosis models offer comprehensive care and social services, utilizing philanthropic support for services that are not traditionally reimbursed.[40, 41] These components may be valuable for considering a model for a chronic, neurodegenerative condition like PD.

Table 2 | PD Clinical Trial Models

Model	Description
UK Wearables Model	The UK Wearables model uses a Parkinson's Kinetigraph (PKG) to monitor patient movements at home to look for signs that medications may need to be adjusted.
Care Coordination for Health Promotion and Activities in Parkinson's Disease (CHAPS)	The CHAPS model is a nurse-led proactive care management intervention that was administered in five United States Veteran's Health Administration medical centers.[36]
ParkinsonNet	This is an interdisciplinary home visit program where a team of specialists (movement disorders doctor, a nurse, a research coordinator, and a social worker) make four visits to patients' homes and provide care over telehealth over one year.[37]

Proposed Care and Payment Model

We propose a novel mode[a] for PD care, services, and payment approaches that can be adjusted for different levels of infrastructure and resource capabilities. The model is designed to be implemented through CMMI because nearly 90 percent of individuals with PD are eligible for Medicare, and CMMI has recently implemented models for chronic and progressive conditions, including dementia. This also could be implemented by commercial payers or accountable care organizations (ACOs).

Table 3 | Components of a Proposed PD Care Model Framework

Model Entry	• PD Diagnosis
Model Exit	• Entry into assisted living facility, entry into hospice, death
Key Roles	• Care Coordinator (often nurse or social worker, but could potentially be any profession) • Financial counselors • Educators for both patients and caregivers
Key Providers	• MDS/Neurologist • Primary Care • Physical Therapist • Speech Therapist • Occupational Therapist • Clinical Social Worker • Nurse/PD Nurse As needed, add: • Neurosurgeon • Neuropsychologist • Additional Specialists
Non-Medical Services	• Exercise Classes • Education (patient/caregiver) • Peer Support Groups • Home safety assessments
Medical Services	• Telehealth • Home Visits • Behavioral Health Services • Respite care for caregivers • Proactive Care Coordination with care plan development • Medicare Part A & B services

Model Components

The proposed model includes components from current models as well as those that stakeholders identified as important for advancing a positive patient experience and high-quality care. **Table 3** provides an overview of the components that could be adjusted according to the care setting, data infrastructures, patient and caregiver preferences, and system resourcing.

This proposed model:

- Utilizes proactive care management with multidisciplinary care teams to deliver holistic care throughout a patient's disease progression. Because the condition is degenerative, the model supports earlier interventions that can delay disease progression and decrease costly events, such as inpatient stays and ED utilization, while maintaining a steady quality of life across disease stages. As such, this model could be long-term (10+ years) to account for both the nature of the disease and to measure long-term cost savings.
- Is intended to be flexible and adaptive to patient needs, existing resources, and future therapeutic advancements. Disease stage does not automatically determine the specialists or services that a patient can receive, but care coordinators and care managers can use it as a tool to anticipate patient needs as they progress (Appendix A). Disease stages can serve as a guide for treatment pathway, but are not intended to be prescriptive or replace treatment guidelines. Providers and care coordinators can use the model to proactively provide care or align with social services according to a patient's specific needs.
- Lends itself to innovative additions as technologies improve and research reveals new insights into the disease. For example, the discovery of a biomarker may allow for earlier diagnosis of PD, which will enable earlier targeted interventions that can delay progression. Current clinical trials are focused on evaluating interventions in the early stages of the disease, so reimbursement for earlier disease stage management could increase to both improve

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[a] The model was informed by a literature review, 10 semi-structured interviews with experts, five semi-structured patient interviews, and a private workshop. After conducting the literature review and interviews, key ideas for what might be part of an ideal care model for PD were presented in a private expert workshop in October 2023.

outcomes and decrease other medical costs over time. Additionally, expanded use of digital health technologies, such as remote patient monitoring, could alert care teams to more timely interventions. However, the benefits of remote patient monitoring must be balanced with the burdens of adding data analysis to care teams. As research on this type of data collection progresses, the potential exists to integrate digital health and data analysis into the calculated PMPM payments.

Model Entry and Exit

Patients would be eligible for the model upon diagnosis of PD. Family physicians, internists, or neurologists generally make PD diagnoses, though MDS have the highest rates of accurate diagnoses.

As awareness of PD and its early symptoms continues to become more widespread, and as researchers continue to search for biomarkers, these advancements may allow for earlier diagnosis of PD, allowing physicians to administer interventions earlier in disease progression. If a biomarker is identified, patients may be have a higher risk for PD much earlier in life, potentially leading to earlier diagnoses before symptoms even begin. When a disease-modifying therapy is approved, there may be even greater patient and provider uptake of biomarker screening. In this case, the care model may need reevaluation, but PD-related care could focus on slowing progression or evaluating patients for symptom onset. Patients would exit from the model when entering assisted living facilities, beginning hospice care, or upon their deaths.[b]

Key Roles and Providers

This proposed care model centers around multi-disciplinary care teams and care coordination. Models that included care coordinators found that patients and physicians appreciated having one role to streamline the coordination of referrals, appointments, and care.

Patient access to a variety of specialists becomes critical as the disease progresses and as symptoms arise or worsen. Both current models and the expert workshop reinforced that the core clinical care team could involve a multitude of roles and professions, including an MDS or neurologist, primary care provider, physical therapist, speech therapist, occupational therapist, clinical social worker, and a nurse/PD nurse. Other specialists can be brought in as needed, depending on the type and severity of patient symptoms. As a patient progresses into mid- or advanced[c] disease stages, adding neurosurgeons or neuropsychologists to a patient's care team may be particularly beneficial as neurosurgical interventions may be more appropriate than in early stages. Regardless of the precise makeup of the care teams, the teams may provide certain key medical services within the care model. Although care teams would ideally be able to fulfill all the actions below, incremental steps towards implementation of each action below would still help create a more supportive care environment for individuals with PD.

Services (Medical and Non-Medical)

Telehealth and Home Visits: The proposed model can include supports and reimbursement for telehealth and home visits in all stages of the disease. Flexibility in where patients can receive their care is important as patients progress in their disease and may have trouble getting to appointments, and for patients that do not live near MDCs. The Rush Home Care trial, which implemented interdisciplinary home visits for homebound patients, showed that providing both telehealth and home-based care—including home safety assessments to identify potential hazards—can lead to better outcomes for more advanced individuals with PD.

Behavioral Health Services: Some of the most common non-motor symptoms of PD include depression, anxiety, and apathy. Interviews with patients highlighted the importance of behavioral health supports, including access to behavioral therapy, peer support networks, and providers with knowledge of the behavioral health symptoms of PD. Management of these symptoms and relevant medications can be complex; behavioral health care services and providers could be integrated into PD care, with psychiatrists and psychologists integrated into care teams when necessary.

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[b] Experts in the private workshop identified hospice care as one aspect of care that can drastically impact both patient and caregiver quality of life. There may be an opportunity to incorporate hospice care into PD care models in the future. One step towards this would be to involve the patient's primary care manager in hospice care planning.

[b] Classifying patients within progression stages of PD can allow for more targeted. For implementing the proposed model, we suggest loosely categorizing patients into early, mid, and advanced disease stages (see **Appendix A**).

Respite Care: Similar to the GUIDE model for dementia care, this proposed model can provide respite care to caregivers for mid- to advanced stage patients. Stakeholders from the interviews and workshop relayed that the burden on caregivers can be significant, especially as patients progress into more advanced disease stages. Monthly payments for respite care will help alleviate some caregiver burden.

Supporting Non-Clinical Services: Experts emphasized the importance of having a care coordinator for ensuring regular patient care touchpoints outside of office visits. For example, reimbursement for care coordination services such as calling the patient ahead of an appointment to discuss any changes in symptoms or quality of life to enable early referrals or scheduling additional appointments with specialists. This would support more proactive, preventive care when compared to the current care delivery system, in which a patient may develop symptoms between biannual or annual visits, and may only discuss these new health concerns at the appointments, which can lead to patients not receiving timely care for changes in their disease progression.

Several professions could potentially effectively fill the care coordinator role in care teams (social workers, nurses, and therapists in particular), but experts agreed that it was more important that care coordinators know PD progression and patient experiences to direct patients to the appropriate resources. Care coordinators also can help relieve some of the current patient and caregiver burdens associated with navigating the health care system and scheduling appointments. One of the key challenges to having an effective, proactive care coordinator under FFS is that care coordination and patient outreach are not traditionally reimbursed which makes proactive care coordination extremely difficult, if not impossible, for many practices. In this proposed care model, proactively distributed payments or lump sum add-on payments would help pay for a proactive care coordination role. These coordinators could reach out to patients quarterly to discuss any changes in patient health status and allow for timely appointment scheduling with the appropriate care team members.

There are additional, non-clinical roles that could improve patient care by offering education or social supports. In particular, patients noted in interviews that financial counselors, educational programs, and formal peer support networks offer unique supports as patients progress in their disease. Even patients who did not find these tools particularly useful for themselves noted their importance and value for other patients.

Medical Products

As the drugs frequently used to treat PD symptoms are primarily self-administered, they are covered by the Part D benefit in Medicare. Many of these pharmacological interventions for PD are generics and are thus relatively inexpensive. However, some of the less-utilized drugs that can greatly contribute to patient quality of life require prior authorization or are not covered. During interviews, patients described varying levels of financial burden associated with their prescriptions.

Given the separate financing and management for clinician-administered (Part B) and pharmacy-dispensed (Part D) drugs in Traditional Medicare, incorporating direct financial accountability for Part D drugs in the model (as with other VBP models in general) is challenging. Thus, this proposed model does not incorporate drugs with care delivery into one payment arrangement. However, because medications are so central to symptom management for PD, future iterations of a PD care model can include considerations for how to best incorporate drugs with care delivery. Medicare beneficiaries are increasingly treated by accountable providers in Traditional Medicare. Further Part D plans are facing stronger pressure to manage drug spending more effectively. Consequently, the need to promote better coordination between drug plans and providers, as a means to reduce overall spending, has become more important. Aligning quality measures between the care model and the Part D Star Rating System can be a key step to encourage this coordination for individuals with PD. Using data from providers on whether patients' conditions are well controlled (e.g., moving from prescription fill to truly aligned outcome measures in Part D) could help encourage data sharing and care coordination between drug plans and providers.

The Merit-Based Incentive Payment System includes measures related to the assessment of mood disorders and psychosis and cognitive impairment or dysfunction for patients with PD. These measures could be coupled with Part D Star Rating measures to ensure appropriate and optimal use of drugs that symptomatically treat mood disorders and cognitive function, such as SSRIs and cholinesterase inhibitors, respectively.

Proposed Payment Approaches

The proposed model includes components from current In contrast to most payment for models focused on condition improvement, there is little precedent for paying for chronic conditions with progressive morbidity. As a result, the payment for this model is designed to support proactive and protracted care, flexibility in how care is delivered, and accountability for long-term outcomes. The payment approach can vary across dimensions, which we describe in further detail below (**Table 4**).

Table 4 | Recommended Components of Alternative Payment Model for PD

Model Entry	Goal	Potential Approach
Payment Approach	Support provider flexibility to furnish care according to patient needs over an extended period of time.	• Capitated (partial or full) payment model in the form of a per-member, per-month (PMPM) payment for all PD-related care. • An incremental step towards PMPM is enhanced FFS payments (e.g., an additional flat monthly amount to support care coordination) or partial capitation for a narrowly defined set of PD services.
Accountability	Ensure an entity (a provider or groups of providers) is responsible for managing some or all of the individual's care and accountable for quality measures.	• Accountability for an individual's total cost of care is appropriate for large, integrated health systems with multi-disciplinary teams. • Smaller, independent practices are not able to take on full-risk. Partial capitation, in which providers are responsible for a narrower set of services may be more appropriate.
Risk Adjustment	Adjust payments to account for changes in an individual's condition and limit provider accountability to factors they can clinically control.	• Composite risk score based on years since diagnosis, age, motor symptoms, non-motor symptoms, cognitive impairment, non-medical drivers of health, mobility/functional status. • Concurrent risk adjustment for acute issue.
Attribution	Accurately identify and assign responsibility for a patient's care to provider panels based on who are most actively involved in managing the patient's condition.	• Retrospective Attribution: would reflect actual care delivered in a PD model, but can limit proactive care planning since providers and patients are unaware of the attribution until after care is provided. • Prospective Attribution: would support proactive care management and coordination and would be ideal for a chronic, degenerative condition. However, prospective attribution is challenging, may lead to inaccuracies if patient care patterns shift, and may potentially misalign accountability.
Benchmarking	Establish clear performance standards that drive quality improvement, cost-effectiveness, and optimal patient outcomes.	• Cohort-based benchmarking based on: - Age - Years since diagnosis - Disease stage or severity - Comorbidities - Types of interventions employed
Outcome Measures	Assess the effectiveness of care by tracking key health indicators that reflect patient well-being, guiding clinical decisions, and supporting accountability in value-based care. Though symptom improvement may not be possible, tracking symptom maintenance or progression rates offers valuable insights into the effectiveness of management strategies.	• A focused set of quality measures tied to the unique clinical needs of PD: - Hospital and Emergency Department Utilization - Medication management - Functional status - Mental health and cognitive screening - Quality of life measurement - Equity in care and outcomes - Caregiver supports

Payment Approaches

In the FFS system, essential PD services like care coordination, caregiver support, and medication management may not be appropriately reimbursed given the time and resources required to provide care. While recent changes have increased reimbursement rates in Traditional Medicare for longitudinal and complex care management,[45] the structure of FFS reinforces a fragmented approach to care delivery. Additionally, no incentive is built in to FFS that encourages providers to promote services that reduce long-term outcomes or reduce downstream costs.

Capitated payment models are an appropriate mechanism to support the longitudinal management of comprehensive care for people with PD. In this proposed payment approach, providers receive a fixed payment per-member, per-month (PMPM), which gives providers the flexibility to tailor care to the evolving health needs of each individual. The PMPM also can facilitate adoption of the model in several ways. Payments are made prospectively each month (or each quarter), giving providers a consistent and predictable revenue stream to manage resources effectively. This structure reduces administrative burdens and allows providers the flexibility to deliver services that align with the patient's health needs, including those that are typically non-reimbursable under traditional FFS systems. Second, depending on the structure of the PMPM, providers can share in the savings generated through efficient care delivery. Appropriate patient care may translate into cost savings for health systems through interventions that reduce inpatient hospital costs, slow disease progression, and ease symptom burden, all of which can lower costs in the long-run. Examples of key performance indicators that could be incorporated into the payment model are described later in this section.

Given differences in capacity, workforce, and resources across different care settings, we propose three strategies for designing the PMPM:

1. **Full Capitation —** The PMPM is an all-inclusive base payment that covers an individual's total cost of care. Providers would assume total financial cost for managing the patient's care. This is appropriate for providers that have the capabilities, workforce size, infrastructure, and sufficient patient empanelment to spread risk, such as those in integrated health care systems.
2. **Partial Capitation —** Partial capitation that focuses on a narrower set of services (e.g., neurological and physical therapy). This is appropriate for independent practices, providers with a smaller patient empanelment, or providers inexperienced with advanced risk-sharing arrangements.
3. **Enhanced FFS Payments —** As an incremental step towards capitated payments, providers could receive a fixed amount on top of their existing FFS revenue. These enhanced payments help cover the time spent on vital yet often non-reimbursable activities, such as exercise therapy, extended patient consultation, care planning, or patient and caregiver education.

Accountability

For individuals with PD, who often receive services from multiple providers, assigning accountability reduces the risk of uncoordinated care. Assigning clinical and financial accountability to a provider can improve treatment oversight, minimizing care gaps and unnecessary treatments. However, providers may have limited control over the full spectrum of services a patient receives, especially given the range of providers that may be involved in PD care. Accountability and reimbursement should match their capacity to effectively manage the services they deliver.

To incentivize coordination across practices, accountability can be shared across multiple independent practices. Practices would share financial savings (or losses) based on the percentage of care they provide to the patient. While financial incentives alone may not drive participation, the flexibility to offer non-traditionally reimbursed services and the reduced administrative burden—enabled by proactive care coordinators—could motivate practices to participate in the model. The payment model can be tailored to the context in which providers operate. Large integrated health systems or multidisciplinary practices can deliver a broad range of services and manage an individual's entire care, giving them greater control over total care costs and the ability to participate in comprehensive cost-of-care models. In contrast, smaller or independent practices have less influence over total care costs and can assume financial risk that reflect their capacity to manage the services they provide.

One potential approach is to nest the payment model within a broader total cost-of-care model, such as those used in ACOs. This strategy involves carving out PD-specific service lines, focusing the payment model on services directly related to PD care while still fitting within a larger population-based model. Nesting these acute episode models within longitudinal specialty payment reforms encourages specialists to remain engaged in the patient's entire care journey, supports team-based care and analytics, and enables specialists to reduce costs and improve outcomes in acute episodes—potentially preventing some episodes altogether.[46] If acute episode payments for procedures or hospitalizations are included, they could be handled separately while ensuring that PD-specific care remains coordinated within the broader payment framework. The challenge with implementing a nested model would be clearly defining what qualifies as PD-specific care given the heterogeneous nature of disease symptoms and progression.

Risk Adjustment

Appropriately adjusting payments and risk for PD is challenging both because of the long disease progression and because many of the factors that drive PD health outcomes are outside of provider control. PD manifests differently through different pathophysiological pathways and clinical phenotypes that are often influenced by non-clinical factors, such as genetic predisposition and environmental factors. This variation in patient complexity, along with the progressive nature of PD, requires frequent changes to the amount providers are paid in order to account for differences in health care utilization and costs.

Payments can therefore be adjusted to account for changes in an individual's underlying health condition. One approach is to adjust payments as the individual advances into a new disease stage, using the stages proposed by traditional clinical frameworks. As the patient progresses into more advanced stages, providers would receive an upwards payment adjusted to account for increased services. Although administratively simple, this step-like approach would result in abrupt payment increases that do not appropriately reflect the gradual progression of PD.

A more gradual and nuanced approach that adjusts payments in alignment with the continuous and individualized progression of PD rather would be the ideal approach. Since disease progression, biomarker profiles, and symptom manifestation varies from person to person, a comprehensive set of factors may support more precise risk adjustment. The development of a composite, weighted index that integrates a broad range of inputs, including assessments of motor and non-motor symptoms, mobility and functional status, comorbidities, self-reported outcomes, social risk factors, and demographic information can better capture risk adjustment. This index can be informed by widely-used, validated, and reliable tools such as the MDS-Unified Parkinson's Disease Rating Scale and Parkinson's Disease Questionnaires, which offer systematic and quantifiable methods for evaluating disease progression, functional capacity, and quality of life. With CMS now reimbursing for regular Social Determinants of Health Risk Assessments, these scores can be integrated into the index to account for patients who may benefit from higher PMPM amounts to account for non-medical services that may improve patient quality of life.[47] Additionally, the index can account for age and the duration since the onset of motor symptoms, as evidence strongly indicates that these factors significantly influence the manifestation of PD.[48]

Ideally, risk adjustments capture current changes in a patient's condition. However, most risk adjustment methods incorporate data from the prior year, leading to delays in adjusting payments for newly arising conditions or sudden health deteriorations. Concurrent risk adjustments, as currently used in CMMI models like ACO REACH High-Needs Track, use current patient data (e.g., recent clinical encounters) to allow for more immediate responses to health needs. Individuals with PD frequently experience a deterioration in symptoms after a hospitalization, and are at higher risk for additional hospitalizations.[49] Ultimately, the availability of data will determine the risk adjustment approach for this payment model. Health plans with limited enrollee data might find it challenging to implement concurrent adjustments effectively. However, MA plans have more continuous enrollee eligibility and may have sufficient data to make this a viable and practical option.

Attribution

The goal of attribution is to accurately identify the patient population for which an accountable entity or participating practice will be held accountable during a performance period. This involves not only honoring patient preferences for provider selection, but also ensuring that the accountable entity or practice has the capability to effectively coordinate and improve the patient's care. Given the complexity of PD, accurate patient attribution is crucial for the successful implementation of a value-based payment model that rewards high-quality, patient-centered care.

Attribution for a PD care model would ideally be prospective, which would involve assigning patients to a provider before the payment performance period begins and offer greater predictability. However, prospective attribution may compromise accuracy if a patient's care needs or patterns shift during the performance period, and this method tends to include more seriously ill patients at high risk of death, leading to higher per-patient expenditures.[50] On the other hand, retrospective attribution would reflect actual care delivered in a PD care model, but would limit the key model component of proactive care planning since providers and patients are unaware of the attribution until after care is provided. Balancing the benefits of predictability with the potential for increased expenditures is essential to selecting the most appropriate approach.

The next step is to determine whether attribution is voluntary or based on claims data. Voluntary attribution would allow individuals with PD to select the provider they feel is most accountable for their care, which is particularly important for managing complex, chronic conditions. Validating patient selection with claims data can be helpful because claims can often indicate ongoing care relationships. Claims-based attribution offers more objectivity than voluntary attribution alone by ensuring patients are linked to providers actively managing their care. Qualifying services for claims-based attribution could include claims for regular PD consultations with providers, medication management, wellness visits focused on chronic disease, mental health services addressing cognitive and emotional challenges, and relevant hospital or emergency visits for PD-related complications. However, fragmented care, inconsistent coding, and the involvement of multiple specialists complicate accurate attribution based solely on billing information. To improve accuracy, using a multi-year claims window and ensuring precise specialty designations in claims data helps prevent misattribution in PD models.

Another potential attribution option is to utilize a multiple attribution model. These models assign a patient to more than one provider or provider group. This approach may be best suited for the proposed PD care delivery model in which a multidisciplinary team collaborates to manage the patient's condition. Team-based attribution in this context ensures that all providers contributing to the patient's care are recognized, fostering collaboration and enhancing accountability for patient outcomes. By attributing outcomes to the entire care team rather than a single provider—and potentially even weighting attribution based on care responsibilities[51]—this model can more accurately reflect the quality and coordination of care provided, driving improvements in treatment effectiveness for individuals with PD.

Benchmarking

Benchmarking allows assessment and comparison of the performance of health care providers against quality and efficiency targets. Benchmarks could reward both improvement and sustained excellence over time. Typically, benchmarks rely on historical spending data, regional variations, or comparisons with other models. For degenerative conditions like PD, traditional benchmarks—whether historical or regional—may fall short of providing meaningful, actionable insights. This is especially true given that individuals with PD frequently have multiple comorbidities and experience unpredictable acute episodes, complicating the establishment of consistent pricing models.

Cohort-based benchmarking may offer a more precise and effective framework for setting financial benchmarks by allowing health care providers to evaluate performance based on specific patient groups, or cohorts, that share key characteristics.[52] Cohort-based benchmarking is a method of performance evaluation that compares health care outcomes, costs, or quality metrics within specific patient groups (or cohorts) that share similar characteristics. Cohort-based benchmarking allows providers to predict financial and clinical outcomes with greater accuracy. This ensures that care models and cost structures are precisely tailored to the unique circumstances of each patient group, rather than relying on a one-size-fits-all approach that can lead to misaligned benchmarks. Cohorts could be defined by factors such as disease stage (early vs. advanced), years since diagnosis, severity, comorbidities (e.g., cognitive impairment), or the types of interventions employed (e.g., medication management, physical therapy, or surgical interventions like deep brain stimulation).

While traditional benchmarking approaches often suffer from limited long-term data for conditions like PD, cohort-based benchmarking maximizes the value of currently available data. By focusing on smaller, more homogeneous groups, this approach can reveal patterns and trends that would likely be obscured in a broader population analysis. Given the heterogeneity of the population with PD, this type of data could lead to more accurate and effective interventions than broad, population analyses.

Another potential approach to benchmarking for the PD model is using shadow payments, a simulation tool used to model financial metrics over time without affecting actual reimbursements. By applying proposed payment rules to existing data, health care organizations can compare shadow payments with real payments under traditional fee-for-service models. This allows stakeholders to assess how well new benchmarks align with the financial realities of PD care, test risk-adjusted payments for patients with varying disease progression or comorbidities, and evaluate potential cost savings or increases across different patient cohorts. Through shadow payments, providers also can test the long-term financial viability of the proposed model, ensuring that payments remain aligned with evolving care needs as PD progresses.

Performance Measures

To measure the value of care provided in this model, a focused set of quality measures tailored to the unique clinical characteristics of PD is essential. These measures could encompass service utilization, clinical processes, and patient-reported outcomes, ensuring a comprehensive evaluation of care quality.

While clinical outcomes remain ideal measures, there is currently no consensus on the most effective performance measures for PD. Research shows limited correlation between adherence to existing quality measures and actual patient outcomes in PD care, indicating a need for further investigation and the development of evidence-based performance measures.[53] While substantial symptom improvement may not always be achievable for patients with PD, tracking the maintenance of symptoms or the rate of progression can provide crucial insights into the effectiveness of symptom management strategies. Specific measures could even be co-developed with patients to ensure that they reflect patient priorities and lived experiences.

Despite the lack of consensus on specific measures, key domains could form the basis of a holistic, comprehensive performance measurement framework. These domains can encompass both the clinical and non-clinical aspects of PD care, including:

- Hospital and Emergency Department Utilization
- Medication Management
- Functional Status
- Mental Health and Cognitive Screenings
- Quality of Life
- Equity in Care Outcomes
- Caregiver Supports

Details on each domain, including potential measures, can be found in **Appendix B**.

Other Payment Considerations

These recommended components of a payment model to support comprehensive PD care are primarily designed for Medicare, a key payer in the PD space. The model must be long-term in order to realize cost savings from delaying disease progression—potentially 15 or more years. Most condition-based CMMI models have been episodic but this would be the first long-term model for a specific condition. A feedback mechanism will be necessary during the first few years of the model to adjust the model as needed.

Patients face challenges in diagnosis and receiving care for early disease stages prior to enrolling in Medicare. Cost savings from delaying progression would be mainly realized in later disease stages, when patients are more likely enrolled in Medicare. MA plans may have a greater ability to work with providers and create alternative payment arrangements that can support the roles and services proposed above. MA also has a much greater ability to promote a more efficient use of medications than standalone Part D plans, due to its integrated drug and medical benefits and realizing savings on Part A and B care.

Next Steps

As a complex, neurogenerative disease with increasing prevalence, PD warrants proactive thinking around care and payment. This model describes an ideal care and payment approach for PD; however, several additional steps and implementation considerations need to be addressed to move the model forward.

First, developing appropriate data infrastructure to accurately capture data about the PD population and costs associated with care will be essential. Currently, no established registry or complete database exists (see **Appendix C**), which makes assessments of total population living with PD diagnosis and the total cost of care for PD difficult. Describing total cost of care is a necessary step for understanding the potential cost-saving or cost-neutral impacts of the described model. Future analysis of the existing cost of care could support or allow for improvements in a PD care model. Improving the data infrastructure for PD also would improve the ability to identify and refer patients, and can better track outcomes longitudinally and across payers.

Second, consensus must be established on appropriate performance measures for chronic or degenerative conditions, Particularly considering those with multiple conditions. While some agree on how to measure optimizing or maintaining function and including patient-reported outcomes, no clear, widely agreed-upon PD-specific measures exist that can reflect these ideas. This was echoed in the workshop, in which experts identified defining important outcomes as a challenge to PD care. One initial step forward would be to align value-based care measures with Medicare quality measures.

Third, piloting proof of concept can support payer interest in implementing the model. Integrated or multidisciplinary practices may be most equipped to pilot the full PMPM structure or ACO nesting. Meanwhile, entities that don't have an established multidisciplinary care team can still pilot the care model by adding lump sum payments onto existing FFS payments to cover costs of care that are not adequately reimbursed. Additionally, standardized data collection across pilot programs will enable the evaluation of the model's effectiveness and identify any potential gaps in services.

Finally, some providers and researchers in the workshop voiced that policies allowing for MDS or neurologists to continue to be involved in PD care throughout the period of hospice care would benefit the patient. When a patient enters hospice, they often must choose an approved, covered hospice provider as their main point of care. This can make continued symptom management throughout hospice care from specialists more challenging. Future research should endeavor to explore this issue.

CONCLUSION

Our proposed model incorporates PD care, services, and payment approaches that can be adjusted for different levels of infrastructure and resource capabilities, and aims to more effectively manage symptoms and disease progression through coordinated are and longitudinal management. However, additional work is needed to support uptake and refinement of the proposed care model. Developing further data infrastructure can improve the ability to identify and refer patients for care, and track outcomes over long periods of time and across payers. Research is needed to understand the total cost of care for PD, which is an essential component for assessing cost-saving or cost-neutral impacts of the proposed model and for generating buy-in from payers and providers. Consensus on appropriate performance measures is needed to support model implementation.

The heterogeneity and complexity of individual circumstances for those living with PD necessitates more comprehensive approaches, including nonpharmacological measures such as physiotherapy and speech therapy that are focused on improving quality of life for both individuals and their caregivers. With an increasing focus on identifying biomarkers and working towards disease-modifying therapies for PD, the opportunity exists now to consider the care delivery and payment systems that could best support broad access to improved treatments in the future.

Appendix A | Disease Progression

Classifying patients within progression stages of PD can allow for more targeted interventions and provides the appropriate level of care and services as patients progress in the disease. Both in interviews and in the workshop, experts acknowledged that current staging techniques do not adequately capture the heterogeneity of patient experience, and primarily rely on motor symptoms. For our model, we loosely categorize patients into early, mid-, and advanced disease stages.

Clinicians and researchers have traditionally relied on a five-stage model, developed by Hoehn & Yahr,[55] to describe clinical function in PD to classify patients into disease stages.[56] In this five-stage model, disease progression is defined by the level of clinical disability, with patients progressing through stages as their motor symptoms become more prohibitive. The Hoehn & Yahr staging is a standardized, familiar approach for physicians to categorize PD disease progression. However, the scale was developed before many of the non-motor symptoms of PD were identified and thus neglects the assessment of patient quality of life.

The MDS-Unified Parkinson's Disease Rating Scale (MDS-UPDRS)[57] is another widely used clinical approach to identifying the stage of the disease. The MDS-UPDRS covers 42 items in four subscales, with the first two sections covering patient-reported non-motor and motor aspects of daily living, and the latter two sections including a motor examination and motor complications assessment recorded by the physician. While the MDS-UPDRS may be more comprehensive, it is a more time-intensive endeavor for already burdened physicians, and licensing is required to use the scale.

The Parkinson's Disease Questionnaires (PDQ-39 and PDQ-8) ,[58, 59] are additional sets of scales identified by clinicians and recognized as effective for assessing the progression of PD holistically. Similar to the MDS-UPPDRS, this is a comprehensive approach but the questionnaires are under copyright, creating a barrier to wider usage in clinical settings.

Despite the wide acceptance of the Hoehn & Yahr five-stage disease progression model, the MDS-UPDRS, and PDQs, usage and documentation of these tools are used in research more than in clinical practice. In interviews and in the workshop, clinicians cited time pressures as one of the main reasons they didn't use a scale to formally assess disease progression, though they often have a mental map of patient progression based on symptoms and quality of life. They also noted a trend towards conceptualizing PD progression through three phases: early, mid-, and advanced disease.

In the early stage, patients may experience some motor and non-motor symptoms, but patients are able to live and complete tasks independently. Interventions such as high intensity exercise has shown promise to slowing disease progression, and may be most effective in this stage. Patients may begin to see physical, occupational, and speech therapists, and benefit from medical products such as levodopa. In mid-stages, patients may experience more cognitive symptoms, worsening motor symptoms, and worsening non-motor symptoms that affect daily living, such that patients may need occasional assistance. Medical products such as walkers and wheelchairs are more common in this stage, and patients may benefit from additional specialists or medications to manage symptoms. Clinicians generally agreed that patients tend to move into this mid-stage around 7-8 years following diagnosis. In the advanced stage, symptoms are severe and greatly affect quality of life. In this stage, patients may be reliant on caregivers for daily living tasks, or may go into assisted living facilities. Clinicians noted that advanced stages often occur 10-15 years after initial diagnosis, though this depends on patient comorbidities, inpatient stays, and other medical factors. This three-stage categorization may help create more accurate risk-adjustments when considering the payment necessary to ensure each patient has the resources necessary for PD care.

Appendix B | Performance Measures

Hospital and Emergency Department Utilization: Monitoring health care utilization is critical for assessing the efficiency of care coordination and preventive services in PD management. Individuals with PD often have elevated rates of inpatient admissions and ED visits, making metrics such as hospitalization rates, ED usage, and 30-day readmissions particularly important for determining the value of interventions. Frequent hospitalizations often signal poor symptom management or inadequate outpatient care, highlighting the need for better care coordination. These measures can help identify gaps in care and reduce unnecessary health care utilization, ultimately lowering costs.

Medication Management: Individuals with PD are often on complex medication regimens (e.g., multiple drugs, frequent dose adjustments). Timely medication adjustments improve outcomes and symptom control, while delays or inappropriate adjustments can worsen symptoms and reduce quality of life. Research underscores the persistent challenges in accurately administering medications during hospitalizations, with common issues including missed or delayed doses and the prescribing of contraindicated drugs (e.g., dopamine-blocking medications), which can exacerbate PD symptoms.[60] To address these complexities and risks, performance measures must prioritize timely and precise administration of medications, adherence to PD-specific medication protocols, and the avoidance of contraindicated drugs, ultimately enhancing patient safety and improving care quality.

Functional Status: Functional status reflects a patient's ability to perform essential daily activities, maintain independence, and manage mobility. Given the progressive motor symptoms of PD—such as impaired balance, gait, and coordination—performance measures could focus on interventions like physical therapy, fall prevention strategies, and rehabilitation services that help maintain or improve patients' functional abilities.

Mental Health and Cognitive Screening: Given the high prevalence of mood disorders and cognitive decline in PD, regular screening for these conditions is essential. Performance measures could include the percentage of patients screened annually for depression, anxiety, and cognitive decline to ensure timely intervention and treatment. Tools such as the Montreal Cognitive Assessment and the Patient Health Questionnaire (PHQ-9) for depression can be employed to track cognitive and mental health outcomes in individuals with PD.

Quality of Life Measurement: Integrating patient experience measures helps ensure that care remains patient-centered. Instruments like the Parkinson's Disease Questionnaire (PDQ-39) can assess physical, mental, and social health, helping to ensure that interventions effectively improve or maintain quality of life. Surveys such as the Consumer Assessment of Healthcare Providers and Systems (CAHPS) can further gauge patient satisfaction with care coordination, provider communication, and responsiveness, offering insights into how well care aligns with patient expectations. This approach also ensures that the model addresses the specific challenges Individuals with PD face, particularly in managing non-motor symptoms and maintaining independence.

Equity in Care and Outcomes: Performance measures could prioritize improving access to care, quality, and outcomes for historically underserved populations by explicitly addressing health disparities. Existing measures must be refined to track and reduce inequities in areas such as access to specialized care, utilization of advanced therapies, medication adherence, and preventive services across diverse groups. These measures could assess non-medical drivers of health, promote culturally competent care, and ensure equitable management of non-motor symptoms like depression and cognitive decline.

Caregiver Support: Incorporating performance measures on caregiver support could help address the often-overlooked needs of those caring for individuals with PD. Caregivers face significant emotional, physical, and financial burdens. Performance measures could assess caregiver strain, satisfaction with care, and the availability of social and emotional support, which ensures that these aspects are prioritized alongside patient outcomes. Tools like the Family Caregiver Experience Surveys and Home Health Care CAHPS can capture data on the quality of support caregivers receive from health care providers, their emotional well-being, and satisfaction with care coordination.

Appendix C | Data Sources

Longitudinal patient data collection can play an instrumental role in identifying and addressing gaps in care, and estimating the total costs of care. Different stakeholders have access to different types of data. Electronic health records (EHRs), administrative claims, and registry data are not frequently interoperable across systems or stakeholders. This piecemeal approach to collecting data on PD creates many challenges in understanding the trends in the disease, the patient experience, the effectiveness of treatments, and the quality of current care approaches. These challenges will persist with the potential approval of disease-modifying treatments. Information about patient symptoms, care plans, and provider notes be recorded in EHRs. EHR data is accessible to providers and patients. Some patient data, such as medications, services provided, and diagnoses can be found in administrative claims data, which is accessible to payers. Registries can offer insights into nuanced patient safety and quality of life data over time. Through the National Neurological Condition Surveillance System (NNCSS), national-level recognition exists for the need for a comprehensive surveillance system for PD. This registry will be an integrated system that will track neurological conditions, but this initiative remains in the infancy stages. Absent a national registry, six states have implemented smaller registries for PD, and some health care institutions host their registries.[62]

A diverse range of data sources is needed to capture the multifaceted nature of PD. By incorporating data from different sources, stakeholders can obtain a comprehensive picture of both clinical and non-clinical aspects of patient care. Ideally, these data sources could be interoperable or linked, enabling a more comprehensive understanding of patient health and disease progression. Utilizing these different data sources will not only enable more accurate risk adjustment and resource allocation, but also help refine care strategies, ultimately leading to more patient-centered and responsive models for PD care.

Administrative Claims Data: Claims data provides valuable insights into diagnoses, assessments, and services rendered. However, it falls short in offering a comprehensive view of patient health, especially when it comes to capturing patient-reported outcomes and functional status. For example, Medicare and MA plans use hierarchical condition categories (HCCs) and demographic data to predict a patient's expected health care spending compared to the average patient. However, HCCs are limited in their ability to predict health care utilization because they primarily rely on past diagnoses and do not account for the complexity of disease progression, variations in care needs, or changes in functional status over time. Additionally, HCCs are static and fail to capture the impact of non-medical drivers of health, patient behavior, and other non-clinical factors that heavily influence health care utilization and spending. This limitation makes HCCs useful but incomplete predictors of future health care costs and utilization.[63]

Electronic Health Records: EHRs can fill critical gaps left by claims data by providing more detailed clinical insights into a patient's functional status and quality of life. Data from assessments like the Activities of Daily Living survey or Parkinson's-specific instruments such as PDQ-8 or PDQ-39 can be integrated into risk adjustment models, offering a more nuanced view of disease progression and patient well-being.

Pharmacy Claims Data: Pharmacy claims data can be leveraged to identify patients with advanced PD based on medication usage, particularly the dosages of CD/LD.[64] Tracking medication regimens through pharmacy claims provides a clearer picture of disease progression and can inform risk adjustment scores by correlating drug dosages with disease severity and expected future care needs.

Registries: Patient registries can capture more nuanced safety data, clinical outcomes, and patient-reported outcomes that are often not available through administrative claims or EHRs. However, the costs and administrative burdens of maintaining a registry may be prohibitive for some practices. Expanding towards a national PD registry would standardize outcome tracking, enable longitudinal studies, and support post-market evidence collection for emerging therapies, ensuring seamless access to new treatments.

Digital Tools and Wearables: Biometric data from digital tools and wearable technologies can offer real-time insights into a patient's day-to-day experience, including mobility, tremor severity, and sleep patterns. This continuous stream of data can provide clinicians with a dynamic view of disease progression and symptom fluctuations that would otherwise go unnoticed between clinic visits.

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