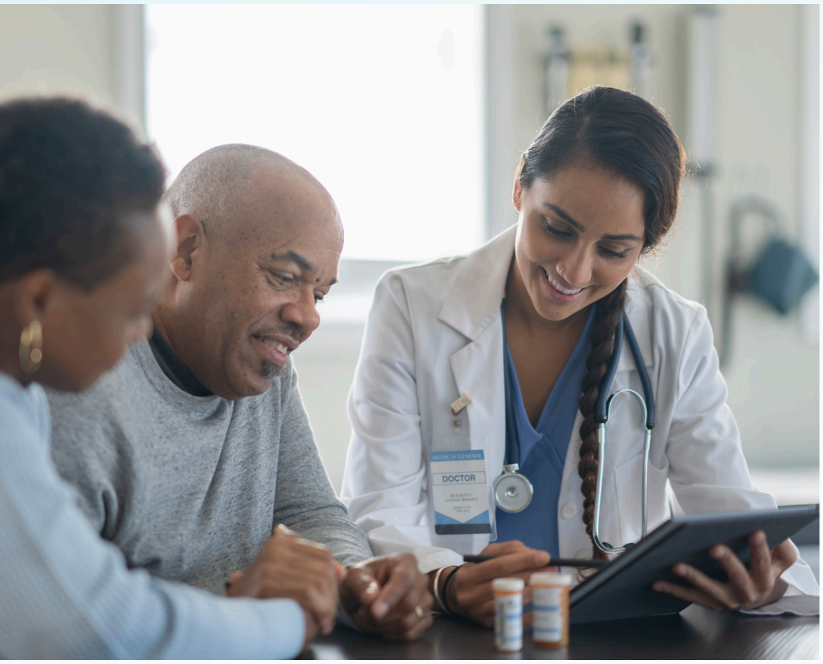

Parkinson's
Foundation

Parkinson's Care and Innovation

A PATIENT-CENTERED AGENDA FOR CHANGE

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Message from the CEO

Since 1957, the Parkinson's Foundation has been a national leader in improving care for people with Parkinson's disease (PD). For more than half a century, we have driven a multidisciplinary care strategy to advance our vision that every person with PD receives the highest quality care possible, regardless of setting.

We are at a pivotal moment in PD care. Parkison's prevalence is increasing and there is a growing shortage of neurologists. Published Parkinson's Foundation research shows that less than 10% of people with PD receive care from a movement disorders specialist. At the same time, we are seeing new approaches and tools emerge across technology, care delivery, and policy that can meaningfully improve the lives of people with PD. Realizing their potential and tackling the challenges faced by the PD community requires a shared vision and coordinated action.

I am pleased to present Parkinson's Care and Innovation: A Patient-Centered Agenda for Change. This agenda was developed using insights from the Parkinson's Foundation National Roundtable on Parkinson's Care and Innovation. Roundtable participants included care leaders, subject matter experts, people living with PD, and innovators from within and outside the PD space across disciplines and sectors.

By incorporating diverse perspectives, the agenda reflects the realities of care across settings, proposes feasible solutions to the most urgent challenges in care, and advances the Foundation's commitment to improving care. It outlines short- and long-term actions for a bold, collaborative approach to change. As with all Parkinson's Foundation initiatives, this work is grounded in the lived experience of people with Parkinson's and care partners.

A common theme that emerged was the need for federal and state policy activation to realize the full potential for care transformation. The Parkinson's Foundation encourages the National Advisory Council on Parkinson's Research, Care, and Services, as established in the Dr. Emmanuel Bilirakis and Honorable Jennifer Wexton National Plan to End Parkinson's Act, to use the solutions within this agenda as key inputs.

The work outlined in this ambitious agenda will, in time, transform care and quality of life for people with PD – improving outcomes, reducing costs, and alleviating the burden faced by care partners. This transformation will require a commitment from PD and healthcare leaders, key healthcare stakeholders, and the Parkinson's community alongside the Parkinson's Foundation.

Sincerely,

JOHN L. LEHR

President & Chief Executive Officer
Parkinson's Foundation

Executive Summary

On September 4, 2025, the Parkinson's Foundation convened the National Roundtable on Parkinson's Care and Innovation. In recognition of the Parkinson's disease (PD) care crisis and in support of the National Parkinson's Project (H.R.2365), Roundtable participants examined, refined, and prioritized solutions to the most pressing challenges in PD care. This was the first Roundtable of its kind, bringing together professionals across disciplines, industries and sectors to lay the groundwork for a national plan for change. People living with PD were critical participants at the Roundtable, ensuring solutions were aligned with the lived experience of managing PD and navigating a complex health care system.

Participants identified four high-impact national PD care solutions outlined in this agenda, to address the immediate needs within each. The agenda expands on the Roundtable discussion by proposing a set of accompanying short- and long-term actions and articulates the Parkinson's Foundation commitment to drive meaningful change in PD care in collaboration with stakeholders nationwide.

Solutions for Transforming Parkinson's Care

Build Community Clinician Capability

to manage Parkinson's leveraging movement disorder expertise, training, and education (hub-and-spoke model).

Develop a Sustainable, Integrated Care Model

that improves care coordination and patient outcomes.

Define the Minimum Clinical Dataset

to support care coordination across settings for people with PD.

Prioritize Patient-Centered Technologies

that are clinically relevant, scalable, and backed by a strong business case.

Background

Parkinson's disease is one of the fastest growing neurological disorders in the world.[1,2]

The United States (U.S.) faces a crisis in PD care. An estimated 1.1 million people in the U.S. live with PD and 90,000 people are newly diagnosed every year.[3,4] The national economic burden of PD, including the cost of treatments and lost wages for people with PD and care partners, is on the rise and expected to surpass $79 billion by 2037.[5] There is a growing shortage of qualified, experienced PD health professionals. Less than 10% of people with PD in the U.S. receive care from a movement disorder specialist (a neurologist with advanced PD training), while 50% receive care from general neurologists and 29% receive care from primary care providers (PCPs).[6] The majority of people with PD have limited access to and/or uptake of the rehabilitation and mental health services that are essential to managing PD.[7,8,9] As the prevalence of PD increases alongside aging of the U.S. population, access to quality PD care continues to erode.

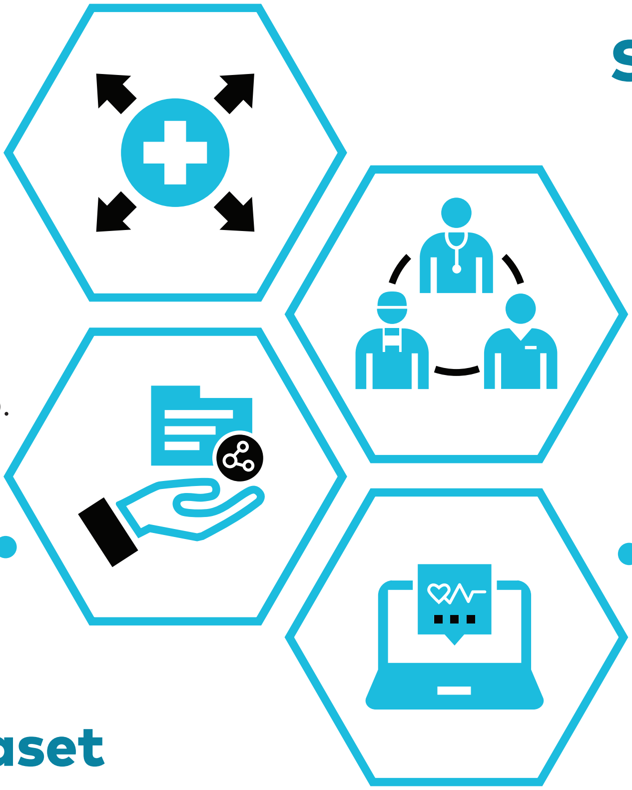
National advocacy efforts have sparked federal action to address the PD care crisis. The National Parkinson's Project (H.R.2365) was signed into law on July 2, 2024, the first-ever federal legislation dedicated to ending PD.[10] It directs the Department of Health and Human Services to carry out a national project to prevent, diagnose, treat, and cure PD and related Parkinsonisms, and calls for the establishment of an Advisory Council on Parkinson's Research, Care, and Services. The Advisory Council will provide community input through annual reports with recommendations concerning the prevention and treatment of PD.[11]

To help inform the Advisory Council on priorities specific to PD care, the Parkinson's Foundation convened the National Roundtable on Parkinson's Care and Innovation on September 4, 2025. The Roundtable brought together physicians, health care providers, people living with PD, health system leaders, care partners, policy experts, and innovators across disciplines and industries—inside and outside of the PD space. Through a multi-step process of pre-work and in-depth in-person discussion, Roundtable participants identified four high-impact national PD care solutions, outlined in this agenda. This agenda also proposes accompanying short-term and long-term actions for each of the solutions, as Roundtable participants repeatedly stressed the importance of identifying practical next steps.

The National Parkinson's Project creates a catalytic opportunity to increase national attention and investment in PD. Fully realizing the promise of the National Parkinson's Project, however, requires that the Federal Government quickly and fully implement the law, starting with seating the Advisory Council. Once the Advisory Council convenes to prepare its first report and recommendations, as required by statute, the solutions detailed in this agenda can serve as key inputs. The solutions are mutually reinforcing; reflect the viewpoint of diverse stakeholders, most importantly that of people living with PD; and establish the foundation for a shared vision and coordinated action across sectors. Together, we can transform care and improve the lives of people with Parkinson's and their loved ones.

Solutions for Transforming Parkinson’s Care

Insights from the Parkinson’s Foundation National Roundtable on Parkinson’s Care and Innovation



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Problem Statement

The significant shortage of movement disorder specialists in the U.S. means that the majority of people with PD receive their care from a general neurologist or PCP, which include physicians, nurse practitioners (NPs), and physician assistants (PAs) ("community clinicians").[12] Parkinson's is a complex, chronic disorder with a broad spectrum of symptoms (from rigidity to speech to depression and anxiety), heterogenous presentation, and a population that often experiences a number of co-morbidities.[13,14,15] Over the course of the disease, PD can impact nearly every aspect of an individual's life, including their career, relationships, and ability to live independently. Disease management requires an individualized balance of medications, devices, and non-pharmacological therapies such as rehabilitation, mental health support, diet, and exercise. In comparison to subspecialists, community clinicians typically have less experience with and expertise in treating PD, and thus diagnosis and care management can pose significant challenges.

With only 660 movement disorder specialists practicing in the U.S., efforts to expand the pipeline of subspecialists are essential. However, these efforts alone will be insufficient to meet the growing needs of Americans diagnosed with PD. Solutions are needed today to extend PD expertise to community clinicians to ensure that all people with PD have access to high-quality, evidence-based care regardless of where they reside or receive treatment.

Solution

Hub-and-spoke models offer a practical, evidence-based method to bridge the gap between movement disorder specialists ("hubs") and community clinicians ("spokes"). Some models focus on education and upskilling. For example, Project ECHO is a well-validated model that uses virtual sessions combining brief didactic presentations with case-based learning to train community clinicians to treat complex conditions such as multiple sclerosis and Alzheimer's disease.[16,17] Other models focus on provider-to-provider collaborations that enable timely access to expert advice and care recommendations (e.g., eConsults or virtual consults). For example, the U.S. Department of Veterans Affairs (VA) uses a hub-and-spoke model to connect six VA Parkinson's Disease Research, Education, and Clinical Centers (PADRECCs),designated Centers of Excellence, with the broad network of VA Medical Centers providing Parkinson's care across the country.[19]

Project ECHO

Project ECHO was developed in 2003 at the University of New Mexico Health Sciences Center to improve care for people living with hepatitis-C and to make quality care accessible to everyone. In the ECHO model, specialists (hubs) share best practices with community-based clinicians (spokes) to support them in providing complex care to individuals without access to specialty care. The model has been used across a broad range of disease areas including Alzheimer's, dementia, diabetes, HIV, and liver disease. Research has shown that the ECHO model increases community clinicians' ability to manage complex health conditions and, as such, increases access to quality care.

There is a promising but limited evidence base for PD-specific hub-and-spoke models in both education and care. PD leaders can build on this to create national PD models that are scalable, sustainable, and reflect what matters most to people living with PD. As a component of these models, and as a means to quickly begin addressing gaps in knowledge, PD leaders can create tools that assist community clinicians with diagnosis and initiating treatment at the point of care. Work on this larger solution begins with establishing an interdisciplinary working group of PD experts, community clinicians, people with PD, and care partners to develop PD-specific models. The working group would be responsible for advancing the following actions, which may be modified as the working group further defines the problem and its solutions.

Short-term Actions (1-3 years)

GOAL:

Develop a PD-specific national or large-scale hub-and-spoke model.

- **Determine the structure of the desired hub-and-spoke models.** Consider:
    - Current best practices from across disease states;
    - Level of relative effort in education/upskilling-based models (e.g., Project ECHO) and care-based models (e.g., eConsult);
    - Integration of existing and evolving reimbursement models;
    - Variation based on resource availability and care settings;
    - Target audience and reach; and
    - Importance of strong leaders, managers, and implementation specialists within health systems who can help develop, test and scale the models.
- **Create program content and resources to support participants. For example:**
    - Develop tools for PCPs to assist with diagnosis and initiating treatment at the point of care and to use in education and training (e.g., Project ECHO).
- **Test and refine hub-and-spoke efforts**, publishing data on impact and outcomes to inform reimbursement policies (e.g., state-based, health system specific).
- **Advance a policy agenda that supports the model's creation.** Potential policy areas to explore include provider reimbursement, medical licensure flexibility (e.g., interstate compact agreements), telehealth coverage, and leveraging funding from the Rural Health Transformation Program.

Long-term Actions (4-7 years)

GOAL:

Expand the model nationally and across relevant disease areas.

- **Scale the model.**
  - Expand programs to ensure relevancy to the array of professionals who provide essential PD care in the community (e.g., NPs, PAs, social workers, physical therapists, occupational therapists, speech-language pathologists, mental health professionals, etc.).
  - Provide active support to leaders within health care delivery organizations to scale the model.
  - Develop incentives and resources to support pilot adoption during scaling.
- **Build the framework for a PD "superhub."**
  - Accelerate upskilling nationwide by training other organizations to launch PD hub-and-spoke programs using the established model.
- **Expand the model to focus on "brain health" more broadly.**
  - Increase the program's relevance to community clinicians who provide care for a variety of disorders by including content on other neurodegenerative diseases.
- **Expand upon a policy agenda that ensures sustainability and enables models to scale broadly.** This could include dedicated federal funding streams or payment models, integration into existing grants or payment models, and Medicare Physician Fee Schedule adjustments.

Implementation Considerations

- **Track record of success:** Educational sessions are virtual, helping to reduce costs; eConsults can be reimbursable, and in some institutions, have attracted external funding.
- **Disease staging:** While a universally accepted biological staging model has yet to be developed for clinical use, there are opportunities to develop guidance on how to treat PD and when to escalate care to a specialist using existing clinical staging models.
- **The Age-Friendly Framework:** Age-Friendly care (guided by the 4Ms: What Matters, Medications, Mentation, Mobility) is ideally suited to PD care and should be considered as part of hub-and-spoke program content to support the delivery of evidence-based, patient-centered care in community settings.
- **Licensure limitations:** Virtual educational sessions can be convened across state lines. However, eConsults are subject to state licensure requirements, creating complexity for multi-state programs.

Develop a Sustainable, Integrated Care Model

that improves care coordination and patient outcomes.

Problem Statement

Quality PD care, as defined by the Parkinson's Foundation, follows a comprehensive, team-based approach through which care is patient-centered, tailored to the individual, care partners are engaged, and essential services are coordinated across an interprofessional workforce inclusive of rehabilitation, exercise, mental health, and social work professionals.[21] Variability in resources across the U.S. poses a challenge for care coordination. For example, rural communities typically have fewer practicing neurologists and less access to a full, co-located team of interdisciplinary professionals compared to urban communities where there is often, though not always, a greater concentration of academic medical centers that centralize essential services.[22] While there are several examples of care models designed to improve PD care coordination, these models are highly site-specific with limited generalizability across other care settings and geographies.[23,24]

Solution

People with PD, care partners, and clinicians need a flexible, evidence-based, integrated care model that can be adapted to a variety of settings and resources. The goals of an integrated care model include improving access to essential services, enhancing care coordination, accelerating time to diagnosis and treatment, improving adherence to evidence-based treatment, slowing symptom progression, and reducing avoidable and costly harm. It requires a team-based, protocol-driven approach that unites neurology, primary care, rehabilitation, pharmacy, mental health, social work, and care navigation around a single shared plan, common data, and closed-loop referrals leveraging an integrated electronic health record. An integrated model optimizes disease-specific outcomes, patient and care partner functional goals, and health-related quality of life over time.

Design and validation of such a model begins with establishing an interdisciplinary working group of PD experts, people with PD, payors, and care partners. This working group would be responsible for advancing the following actions to better understand the clinical and financial outcomes of implementing an integrated care model at scale. These actions may be modified as the working group further defines the problem and its solutions.

Short-term Actions (1-3 years)

GOAL:

Design and validate an evidence-based integrated care model.

- **Evaluate the evidence base of current best practice care models in PD and other relevant diseases.**
  - Focus on data specific to outcomes, scalability, and sustainability.
  - Examine the multidisciplinary care model and approach used by the VA to provide care to many of the over 110,000 veterans with PD.[27]
  - Reference existing value-based payment models (e.g., the GUIDE Model and the ACCESS Model[25]) to better understand opportunities to engage CMMI on expanding them to PD and other neurological conditions.[a]
- **Design an integrated care model based on available evidence.** Consider:
  - What matters most to people with PD and care partners;
  - Core objectives of the model;
  - Team composition and leadership/management capabilities required to deliver the model at scale;
  - Role of Advance Practice Providers (APPS) (e.g., nurse practitioners and physician assistants);
  - Importance of a single point of contact for the patient to streamline navigation and care coordination;
  - Services included (e.g., care navigation, rehabilitation, care partner supports);
  - Coverage and reimbursement;
  - Variation based on care setting; and
  - Business case and opportunity to support the model leveraging existing payment policies (e.g., chronic care management)
- **Convene a meeting of key payors and related stakeholders to build coalition for the new model and to validate total cost of care and quality improvement goals.**
- **Pilot test and refine the model in multiple care settings, publishing results on impact.**
  - Focus on designing, testing, and publishing studies which demonstrate the clinical and financial impact with the goal of defining a linked value-based payment model.

Long-term Actions (4-7 years)

GOAL:

Ensure broad dissemination and uptake of the integrated care model.

- **Drive uptake of the care model components**. For example:
  - Promote implementation across care settings and regions through focused peer-learning groups.
- **Consider expanding the model to focus on "brain health" more broadly.**
  - A broader framework would better align patient needs across similar, often overlapping populations and signal to policymakers and clinical leaders that their investments would impact a larger segment of care.
- **Advocate for policy changes at the state level which allow for APPs to operate at the top of their license.**
- **Explore the possibility of a PD care model pilot** or adding PD to existing value-based models through the Centers for Medicare & Medicaid Services (CMS) Innovation Center.
  - Advance parallel value-based alternative payment models through state Medicaid programs and align with state investments in rural health transformation.

Implementation Considerations

- **Strength of the business case:** Payors and clinical leaders will need to demonstrate that the care model enables cost savings, financial sustainability, and improved patient outcomes under the current payment schema.
- **Care team education:** Uptake will depend on clinician education starting in academic training programs and extending through continuing education curriculums for practicing clinicians.
- **Care partners:** In addition to support with activities of daily living and medical tasks, the majority of care partners in the U.S. (non-PD specific) are also involved in care coordination. An integrated care model combined with policy considerations (e.g., tax credits) can help to address the impact on care partners.

The Role of APPs

APPs hold significant and proven potential to improve access to care in light of national shortages in movement disorder specialists and physicians. However, their care team roles are highly variable, exacerbated by variation in state scope of practice laws, patient perceptions, physician perceptions, relatively lower reimbursement, and limited specialty training programs in neurology and movement disorders. The working group should consider how the role of APPs can be enhanced to help address the growing demand for neurological care.

- [a]GUIDE: Guiding an Improved Dementia Experience Model
- ACCESS: Advancing Chronic Care with Effective, Scalable Solutions Model
- CMMI: Centers for Medicare and Medicaid Innovation Center

Define the Minimum Clinical Dataset

to support care coordination across settings for people with PD.

Problem Statement

Parkinson's is a chronic condition that people often live with for decades and that, as previously noted, requires care from a variety of health professionals across a multitude of care settings. Ideally, when a person with PD moves between clinicians and settings throughout their disease journey, their providers would be able to efficiently and securely share information with one another. Despite advances in interoperability standards, the ability to share clinically meaningful, and computable data related to PD remains nascent. This constrains the ability to coordinate care, measure outcomes, and scale research across the health ecosystem.

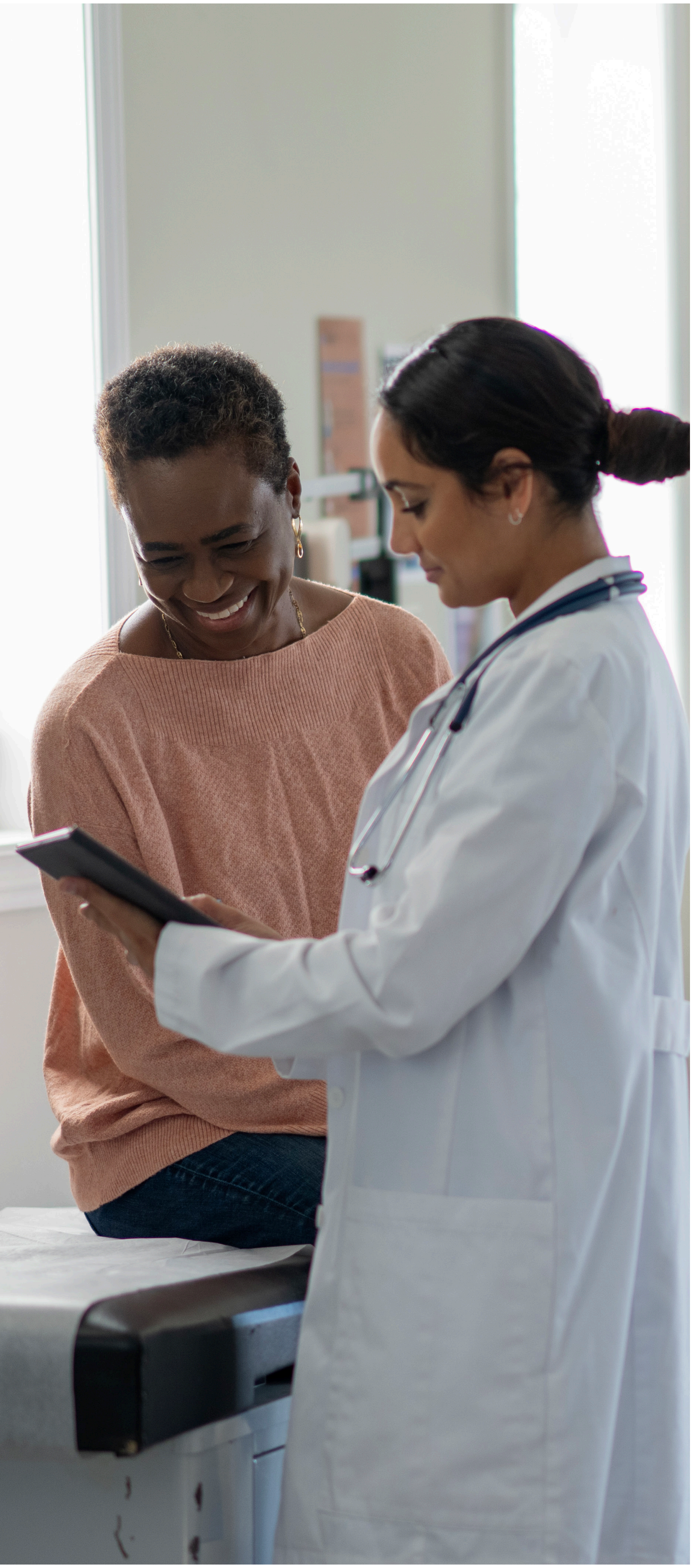
Past efforts to standardize PD data include the International Consortium for Health Outcomes Measurement (ICHOM) Set of Patient-Centered Outcome Measures for PD, the National Institute of Neurological Disorders and Stroke (NINDS) Common Data Elements for PD, and the Michael J Fox Foundation consensus data elements for PD registries. However, these efforts tended to focus on specific use cases, and, while feasibility and usability were considered, widespread adoption remains limited.

Solution

To guide clinical and shared decision-making and to communicate disease impact and progression across care settings, the PD community needs an expert consensus-driven, standardized, computable, clinically and functionally meaningful and feasible minimum data set. This universal, core set of data elements serves as the foundation of a common language for all PD-related use cases and supports optimal care delivery across all settings. Once the data elements are defined, operationalizing them across clinical workflows and the broader health IT ecosystem will require a practical and coordinated implementation strategy to ensure the standards are accepted and adopted by clinicians, integrated into EHR workflows, and supported by health systems, payors, and public health entities.

Establishing these data standards will provide groundwork for future innovation, including semantic use of AI and other emerging technologies to enhance PD care and accelerate discovery. It will also support development of pertinent data sets, which build upon the established minimum data set, and define additional consensus data standards to support additional use cases, including care coordination, quality improvement, clinical trials, epidemiology, health outcomes research, precision medicine, genomics, and biomarker testing. As data standards are being developed, it will be important to consider and identify what entity or entities are best positioned to build and maintain the data and standards (e.g., government, medical societies).

Defining a standardized minimum data set begins with establishing an interdisciplinary working group of PD clinical experts, people with PD, care partners, researchers, public health leaders, policy makers, regulatory agencies, payors, EHR vendors, and standards development organizations. Including people living with PD is essential to ensuring the initial minimum data sets reflect what matters most to those living with the disease. This working group would be responsible for advancing the following actions, which may be modified as the working group further defines the problem and its solutions.



Short-term Actions (1-3 years)

GOAL:

Define the standardized minimum data set and implementation strategy.

- **Define and prioritize the use cases for PD-specific minimum data set.**
    - Use cases will guide selection of data elements for the minimum and pertinent data sets, an approach successfully used in other domains (e.g. mCODE, CodeX, CardX projects).
- **Define and test the selected standard data elements.**
    - This will require a consensus-driven process that reviews and harmonizes existing standards across use cases and real-world health care settings.
    - Incorporate digital endpoints as appropriate (e.g., motor fluctuations, gait, freezing episodes).
    - Engage FDA on endpoint selection and developing validated surrogate endpoints.
- **Develop options for data collection and governance.**
- **Establish a shared community roadmap for PD data standards** aligned with existing national data standards in coordination with the Assistant Secretary for Technology Policy/Office of the National Coordinator for Health Information Technology (ASTP).

Long-term Actions (4-7 years)

GOAL:

Execute on the implementation strategy.

- **Publish and promote the data set.**
  - Include summaries of their development and practical guidance for implementation.
- **Establish a governance and maintenance process to:**
  - Align on the entity responsible for building and maintaining the data set and standards;
  - Ensure data sets remain clinically relevant and support broad use cases; and
  - Strengthen collaboration with existing large-scale PD programs, including state PD registries and the CDC National Neurological Conditions Surveillance System (NNCSS).
- **Integrate and implement a consensus framework and roadmap for PD data standards in coordination**, driven by use cases and published minimum data sets, within a coordinated strategy aligned with national interoperability frameworks such as HL7, USCDI, and TEFCA.[b]

Implementation Considerations

- **Data standards and acquisition:** To ensure consistency and scalability, data elements must be well defined, standardized, computable, and aligned with established data standards (e.g., HL7 FHIR).
- **Effort and resources required to align data standards across the health care ecosystem:** Achieving wide-spread adoption of standardized data sets will take significant collaboration, expert consensus, and stakeholder buy-in across government programs, health systems, EHR vendors, payors, patient groups, and more.
- **Organizational oversight:** It will be essential to identify and define what entity will be responsible for building and maintaining the data and standards overtime.

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[1] HL7: HL7 (Health Level Seven) is defined as a set of international standards for exchanging, integrating, and retrieving electronic health information.
USCDI: United States Core Data for Interoperability is a standardized set of health data classes and elements for nationwide, interoperable health information exchange.
TEFCA: Trusted Exchange Framework and Common Agreement is a government initiative that establishes a unified, secure, and interoperable national framework for exchanging electronic health information.

Prioritize Patient-Centered Technologies

that are clinically relevant, scalable, and backed by a strong business case.

Problem Statement

Innovation in PD technology is accelerating. A variety of tech-driven tools are now available to support people with PD, care partners, and clinicians across settings. For example, AI has demonstrated the ability to screen for and diagnose PD and assess disease severity, and data from body-worn sensors (i.e., wearables) can now be used in the assessment of motor symptoms, including dyskinesia and gait disturbances.[28,29] Data from wearables has also been used to enhance physical therapy.[30]

Despite these advances and their potential to positively impact care, tech-driven tools have not been widely adopted by people with PD or their care teams. For example, only 24% of people with PD report using wearable devices, like smartwatches, to manage their disease.[31] And of that 24%, the majority do not use wearable devices to their full clinical potential. Though many wearables can now track symptoms, falls, and treatment effects, and share data directly with clinicians, people with PD primarily use wearables for simpler tasks like tracking medication timing.[32]

The lack of uptake in wearables and other innovations may be due to gaps in access related to age and geography, an evidence base that is still incomplete, and lack of alignment with what matters to people with PD and their care partners, as well as challenges associated with both the integration into clinical workflows and into real-world, day-to-day use. Additionally, most wearables today focus on measurement and lack the needed clarity for consumers on integration into treatment. To address the root causes and capitalize on the momentum in this space, PD technology must be affordable (e.g., covered by health plans), evidence-based, reflect what matters to people with PD and their care partners, provide clear use cases for consumers, integrate seamlessly into clinical care and into every-day use, and provide clinically relevant and easily digestible data for care teams across settings. The technology must also be usable even in communities with fragmented broadband networks.

Solution

A framework to guide PD innovation and investment is essential to ensure new technologies are thoughtfully designed and successfully scaled. It should define core principles that reflect what matters to people living with and caring for PD, support clinical decision-making, and promote financial sustainability. The framework should also clarify the high-value problems to solve, key users and purchasers (e.g., people with PD, care partners, care team members, health systems, health plans, employers), and the policy and financial incentives needed to drive cross-sector collaboration and investment.

Creating this guiding framework begins with establishing an interdisciplinary working group of those who actively participate in the innovation pipeline, including researchers, industry leaders (e.g., life sciences, medtech, digital health), intellectual property professionals, payors, policymakers, investors, and end-users (i.e., people with PD, care partners). This working group would be responsible for advancing the following actions, which may be modified as the working group further defines the problem and its solutions.

Short-term Actions (1-3 years)

GOAL:
Define an innovation framework.

- **Define the PD innovation pipeline.**
    - Demystify steps for prospective innovators, reducing barriers to entry.
- **Define the guiding principles for advancing PD technology.**
    - Principles should be representative of patient, care team, and investor perspectives to ensure products are accessible and effective and have sufficient financial potential for large-scale investment and dissemination.
- **Identify key policy barriers to technology advancement. Potential policy areas to explore include:**
    - Improving FDA and CMS coordination to prevent coverage gaps;
    - Expanding efforts to incorporate patient perspectives in product development; and
    - Telehealth flexibilities and payment parity.

Long-term Actions (4-7 years)

GOAL:

Develop incentives to support implementation of the framework.

- **Develop and implement incentives for innovation, particularly public-private partnerships.** For example:
  - Grant opportunities
  - Low-interest financing for early-stage or translation innovation
- **Consider whether to recommend that innovations address "brain health" more broadly,** not just PD, to promote engagement across disease areas.
  - Scope expansion would increase the total addressable market, encouraging greater investment and uptake.

Implementation Considerations

- **Balanced governance and stewardship:** A neutral working group facilitator will be required to steward framework development, balance public-private interests, and cultivate working relationships between public and private sector representatives.
- **Address risk aversion:** The principles and incentives defined by the working group must ensure risk is balanced across public and private stakeholders. For example, venture capital firms may be hesitant to invest in high-risk high-reward solutions or health systems may be reluctant to adopt new AI tools that may disrupt their operations.

The Parkinson’s Foundation Commitment to Improving Care

As a national leader in Parkinson’s care, the Parkinson’s Foundation will play a key role in advancing the solutions detailed in this agenda. The Foundation is committed to working across sectors to ensure every person with PD receives the highest quality care, regardless of setting. Over the next several years, the Foundation will engage with key stakeholders on the solutions outlined within this agenda.

Build Community Clinician Capability

The Parkinson’s Foundation will expand training, education initiatives, and tools to equip community clinicians with PD-specific knowledge and protocols. The Foundation will partner with centers in its Global Care Network to improve care, exploring opportunities to bridge the gap between movement disorder specialists and community clinicians such as creating educational tools or developing a national PD-specific Project ECHO program. Additionally, the Foundation will look to the experiences of other disease areas to understand impact and outcomes. All efforts will be driven by PD community and clinician feedback.

Develop a Sustainable, Integrated Care Model

Through the Foundation’s Innovations in Care Awards, the Foundation will provide pilot funding for clinical research on new models and approaches for care delivery that improve health and quality of life, and that are grounded in the lived experience of people with PD. The Foundation will also test new workforce development models, like the NP Fellowship in Movement Disorders that focuses on integrating NP expertise into PD care. Findings across projects will be published, and used to expand access, promote efficiency, and improve outcomes.

Define the Minimum Clinical Dataset

The Foundation will continue to lead efforts supporting initiatives that improve PD data informed by what matters most to people living with PD. The Foundation will also establish and follow a PD cohort with genetic, clinical and demographic data, and explore collaborations to support innovative data projects across the care continuum.

Prioritize Patient-Centered Technologies

The Foundation will continue to solicit insights directly from people with PD and care partners about the aspects of PD that most impact their everyday life, what matters to them when choosing a tech-driven PD tool, and the challenges they experience integrating technology into everyday use. The Foundation will use this data to help inform prospective innovators and investors.

Advance a Policy Agenda that Meaningfully Improves Care for People with PD

The Foundation will advocate at the federal and state level for legislation, regulations, and funding to improve access to quality care and address identified policy barriers. Lessons learned from pilot projects, research, and engagement with community members and clinicians will be used to inform new areas of priority policy engagement. Additionally, the Foundation will engage directly with the Centers for Medicare and Medicaid Services (CMS) and the Food and Drug Administration (FDA) on patient and provider centered regulatory policy, coverage gaps, and to explore potential CMS Innovation Center models.

Roundtable Participants

Kathy Blake, MD, MPH	• Chair, Parkinson's Foundation People with Parkinson's Advisory Council • Retired Cardiologist, New Mexico Heart Institute • Former Vice President of Healthcare Quality, American Medical Association
Jon Blum	• Senior Scholar, University of Southern California Schaeffer Institute • Former Principal Deputy Administrator & Chief Operating Officer, Centers for Medicare & Medicaid Services (CMS)
Tom Cassels, MPP	• Managing Director, Manatt Health • Former President and CEO, Rock Health
Morgan Daven, MA	• Vice President, Healthcare Strategy, Alzheimer's Association • Former Strategic Director, Primary Care Systems, American Cancer Society
Alessandro Di Rocco, MD	• Director, Movement Disorders Program, Northwell Health • Former Founding Director, New York University-Langone Fresco Institute for Parkinson's & Movement Disorders • Board of Directors, Parkinson's Foundation
Terry Ellis, PhD, PT, FAPTA	• Professor & Chair, Physical Therapy, Department Director, Center for Neurorehabilitation, Boston University • Board Certified Specialist, Neurologic Physical Therapy
Debbie Gunter, APRN, FNP-BC, ACHPN	• Lead Nurse Practitioner, Emory Healthcare Cognitive Neurology Clinic, Brain Health Center • Faculty, Emory University, School of Medicine & School of Nursing

Glenn Kasman, MS	• Former Member, Parkinson's Foundation People with Parkinson's Advisory Council • Retired Healthcare Executive
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Sneha Mantri, MD, MS	• Chief Medical Officer, Parkinson's Foundation • Associate Professor of Neurology, Duke University School of Medicine
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Cheryl Phillips, MD, AGSF	• Senior Program Consultant, The John A. Hartford Foundation • Board of Directors - Chair, The SCAN Foundation • Past President, American Geriatrics Society

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Roundtable Facilitators

Christiana Evers, MPA	• Vice President, Chief Community Engagement Officer, Parkinson's Foundation
Sheera Rosenfeld, MHS	• Vice President, Chief Strategic Initiatives Officer, Parkinson's Foundation
Emily Buetow, MSSW	• Senior Director, Strategic Initiatives, Parkinson's Foundation
Jared Augenstein, MA, MPH	• Senior Managing Director, Manatt Health
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References

[1] GBD 2015 Neurological Disorders Collaborators. (2017). Global, regional, and national burden of neurological disorders during 1990–2015: A systematic analysis for the Global Burden of Disease Study 2015. The Lancet Neurology, 16(11), 877–897. https://doi.org/10.1016/S1474-4422(17)30299-5

[2] Su, D., Cui, Y., He, C., Yin, P., Bai, R., Zhu, J., Lam, J. S. T., Zhang, J., Yan, R., Zheng, X., Wu, J., Zhao, D., Wang, A., Zhou, M., & Feng, T. (2025). Projections for prevalence of Parkinson's disease and its driving factors in 195 countries and territories to 2050: Modelling study of Global Burden of Disease Study 2021. BMJ, 388, e080952. https://doi.org/10.1136/bmj-2024-080952

[3] Marras, C., Beck, J. C., Bower, J. H., Roberts, E., Ritz, B., Ross, G. W. & Tanner, C. M. (2018). Prevalence of Parkinson's disease across North America. npj Parkinson's Disease, 4(1), Article 21. https://doi.org/10.1038/s41531-018-0058-0

[4] Willis, A. W., Roberts, E., Beck, J. C., Fiske, B., Ross, W., Savica, R., Van Den Eeden, S. K., Tanner, C. M., Marras, C., & the Parkinson's Foundation P4 Group. (2022). Incidence of Parkinson disease in North America. npj Parkinson's Disease, 8(1), Article 170. https://doi.org/10.1038/s41531-022-00410-y

[5] Yang, W., Hamilton, J. L., Kopil, C., Beck, J. C., Tanner, C. M., Albin, R. L., Dorsey, E. R., Dahodwala, N., Cintina, I., Hogan, P., & Thompson, T. (2020). Current and projected future economic burden of Parkinson's disease in the U.S. npj Parkinson's Disease, 6(1), Article 15. https://doi.org/10.1038/s41531-020-0117-1

[6] Pearson, C., Hartzman, A., Munevar, D., Feeney, M., Dolhun, R., Todaro, V., Rosenfeld, S., Willis, A., & Beck, J. C. (2023). Care access and utilization among Medicare beneficiaries living with Parkinson's disease. npj Parkinson's Disease, 9(1), Article 108. https://doi.org/10.1038/s41531-023-00523-y

[7] Goldman, J. G., Volpe, D., Ellis, T. D., Hirsch, M. A., Johnson, J., Wood, J., Aragon, A., Biundo, R., Di Rocco, A., Kasman, G. S., Iansek, R., Miyasaki, J., McConvey, V. M., Munneke, M., Pinto, S., St. Clair, K. A., Toledo, S., York, M. K., Todaro, R., Yarab, N., & Wallock, K. (2024). Delivering multidisciplinary rehabilitation care in Parkinson's disease: An international consensus statement. Journal of Parkinson's Disease, 14(1), 135–166. https://doi.org/10.3233/JPD-230117

[8] Pearson, C., et al. (2023). npj Parkinson's Disease.

[9] Roberts, A. C., Rafferty, M. R., Wu, S. S., Miao, G., Cubillos, F., Simuni, T., Parkinson's Foundation Quality Improvement Initiative Investigators Steering Committee Members, & Parkinson's Foundation Quality Improvement Initiative Principal Investigators.Patterns and predictors of referrals to allied health services for individuals with Parkinson's disease: A Parkinson's Foundation Quality Improvement Initiative study. (2021). Parkinsonism & Related Disorders, 83, 115–122. https://doi.org/10.1016/j.parkreldis.2020.11.024

[10] United States House of Representatives. (2023). Dr. Emmanuel Bilirakis and Honorable Jennifer Wexton National Plan to End Parkinson's Act, H.R. 2365, 118th Cong. Retrieved from https://www.congress.gov/bill/118th-congress/house-bill/2365

[11] Ibid.

[12] Pearson, C., et al. (2023). npj Parkinson's Disease.

[13] Rawls, A., & Okun, M. S. (2025). Parkinson disease. Continuum: Lifelong Learning in Neurology, 31(4), 930–955. https://doi.org/10.1212/cont.0000000000001593

[14] Tanner, C. M., & Ostrem, J. L. (2024). Parkinson's disease. New England Journal of Medicine, 391(5), 442–452. https://doi.org/10.1056/NEJMra2401857

[15] Chaudhary, S. A., Chaudhary, S., & Rawat, S. (2025). Understanding Parkinson's disease: Current trends and its multifaceted complications. Frontiers in Aging Neuroscience, 17, Article 1617106. https://doi.org/10.3389/fnagi.2025.1617106

[16] Pearson, C., et al. (2023). npj Parkinson's Disease.

[17] Alschuler, K. N., Stobbe, G. A., Hertz, D. P., Johnson, K. L., von Geldern, G., Wundes, A., Reynolds, P., Unruh, K., & Scott, J. D. (2019). Impact of Multiple Sclerosis Project ECHO (Extension for Community Healthcare Outcomes) on provider confidence and clinical practice. International Journal of MS Care, 21(4), 143–150. https://doi.org/10.7224/1537-2073.2018-014

[18] Waters, L., Sohmer, D., Goldman, R. E., Bluestein, D., Burnham, K., Clark, P. G., Slattum, P. W., Helm, F., & Marks, J. (2024). Beyond knowledge and confidence: A mixed methods evaluation of a Project ECHO course on dementia for primary care. Gerontology & Geriatrics Education, 45(4), 552–565. https://doi.org/10.1080/02701960.2023.2278097 (pubmed.ncbi.nlm.nih.gov)

[19] U.S. Department of Veterans Affairs. (n.d.) Parkinson's Disease Research, Education and Clinical Centers: National VA Parkinson's Disease Network. U.S. Department of Veterans Affairs. https://www.parkinsons.va.gov/PARKINSONS/Consortium/index.asp

[20] Interstate Medical Licensure Compact Commission. (n.d.). Information for physicians. IMLCC. https://imlcc.com/information-for-physicians/

[21] Centers for Medicare & Medicaid Services. (2025, September 26). Rural Health Transformation (RHT) Program: Overview. CMS. https://www.cms.gov/priorities/rural-health-transformation-rht-program/overview

[22] The John A. Hartford Foundation. (n.d.). Age-Friendly Health Systems Initiative. John A. Hartford Foundation. https://www.johnahartford.org/grants-strategy/current-strategies/age-friendly/age-friendly-health-systems-initiative

[23] Parkinson's Foundation. (n.d.). Our care strategy. Parkinson's Foundation. https://www.parkinson.org/understanding-parkinsons/statistics

[24] Pearson, C., et al. (2023). npj Parkinson's Disease.

[25] Bloem, B. R., Rompen, L., de Vries, N. M., Klink, A., Munneke, M., & Jeurissen, P. (2017). ParkinsonNet: A low-cost health care innovation with a systems approach from the Netherlands. Health Affairs, 36(11), 1987–1996. https://doi.org/10.1377/hlthaff.2017.0832

[26] HealthPartners. Struthers Parkinson's Center. https://www.healthpartners.com/care/specialty-centers/struthers-parkinsons-center/

[27] Feeney, M., Duda, J., Hiller, A., Phillips, J., Evers, C., Yarab, N., Todaro, V., Rader, L., & Rosenfeld, S. (2022). Understanding health care needs among Veterans with Parkinson's disease: A survey study. Fronters in Neurology, 13. https://doi.org/10.3389/fneur.2022.924999

[28] Centers for Medicare & Medicaid Services. Guiding an Improved Dementia Experience (GUIDE) Model. CMS. https://www.cms.gov/priorities/innovation/innovation-models/guide

[29] Centers for Medicare & Medicaid Services. ACCESS (Advancing Chronic Care with Effective, Scalable Solutions) Model. CMS. https://www.cms.gov/priorities/innovation/innovation-models/access

[30] AARP and National Alliance for Caregiving. Caregiving in the US 2025. (2025). https://doi.org/10.26419/ppi.00373.001

[31] Sha, R., Dabus, M. A., Torres Russotto, D. R., Bhakuni, N., & Dabus, G. C. (2025). Innovations in Parkinson's disease: Strategies and novel technologies. Cureus, 17(7), e87309. https://doi.org/10.7759/cureus.87309 (cureus.com)

[32] Moreau, C., Rouaud, T., Grabli, D., Benatru, I., Remy, P., Marques, A. R., Drapier, S., Mariani, L. L., Roze, E., Devos, D., Dupont, G., Bereau, M., & Fabbri, M. (2023). Overview on wearable sensors for the management of Parkinson's disease. npj Parkinson's Disease, 9(1), Article 153. https://doi.org/10.1038/s41531-023-00585-y (nature.com)

[33] Kim, J., Porciuncula, F., Yang, H. D., Wendel, N., Baker, T., Chin, A., Ellis, T. D., & Walsh, C. J. (2024). Soft robotic apparel to avert freezing of gait in Parkinson's disease. Nature Medicine, 30(1), 177–185. https://doi.org/10.1038/s41591-023-02731-8

[34] Hirczy, S., Zabetian, C., & Lin, Y. H. (2024). The current state of wearable device use in Parkinson's disease: A survey of individuals with Parkinson's. Frontiers in Digital Health, 6, Article 1472691. https://doi.org/10.3389/fdgth.2024.1472691 (frontiersin.org)

[35] Ibid.

References in Project ECHO Box:

[1] Arora, S., Kalishman, S., Thornton, K., Dion, D., Murata, G., Deming, P., Parish, B., Brown, J., Komaromy, M., Colleran, K., … Pak, W. (2010). Expanding access to hepatitis C virus treatment—Extension for Community Healthcare Outcomes (ECHO) project: Disruptive innovation in specialty care. Hepatology, 52(3), 1124–1133. https://doi.org/10.1002/hep.23802

[2] Osei Twum, J., Wiles, B., Killackey, T., & colleagues. (2022). Impact of Project ECHO on patient and community health outcomes: A scoping review. Academic Medicine. Advance online publication. https://doi.org/10.1097/ACM.0000000000005000 (pubmed.ncbi.nlm.nih.gov

[3] Donoghue, K. M. (n.d.). Project ECHO: Origin story. Project ECHO. https://projectecho.unm.edu/story/project-echo-origin-story/

About the Parkinson's Foundation

The Parkinson's Foundation makes life better for people with Parkinson's disease (PD) by improving care and advancing research toward a cure. In everything we do, we build on the energy, experience and passion of our global Parkinson's community. For more information, visit **Parkinson.org.**

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