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The National Roundtable on Parkinson's Care and Innovation: A Multidisciplinary, Multi-Sector Convening Aimed at Addressing the Most Pressing Challenges in Parkinson's Care

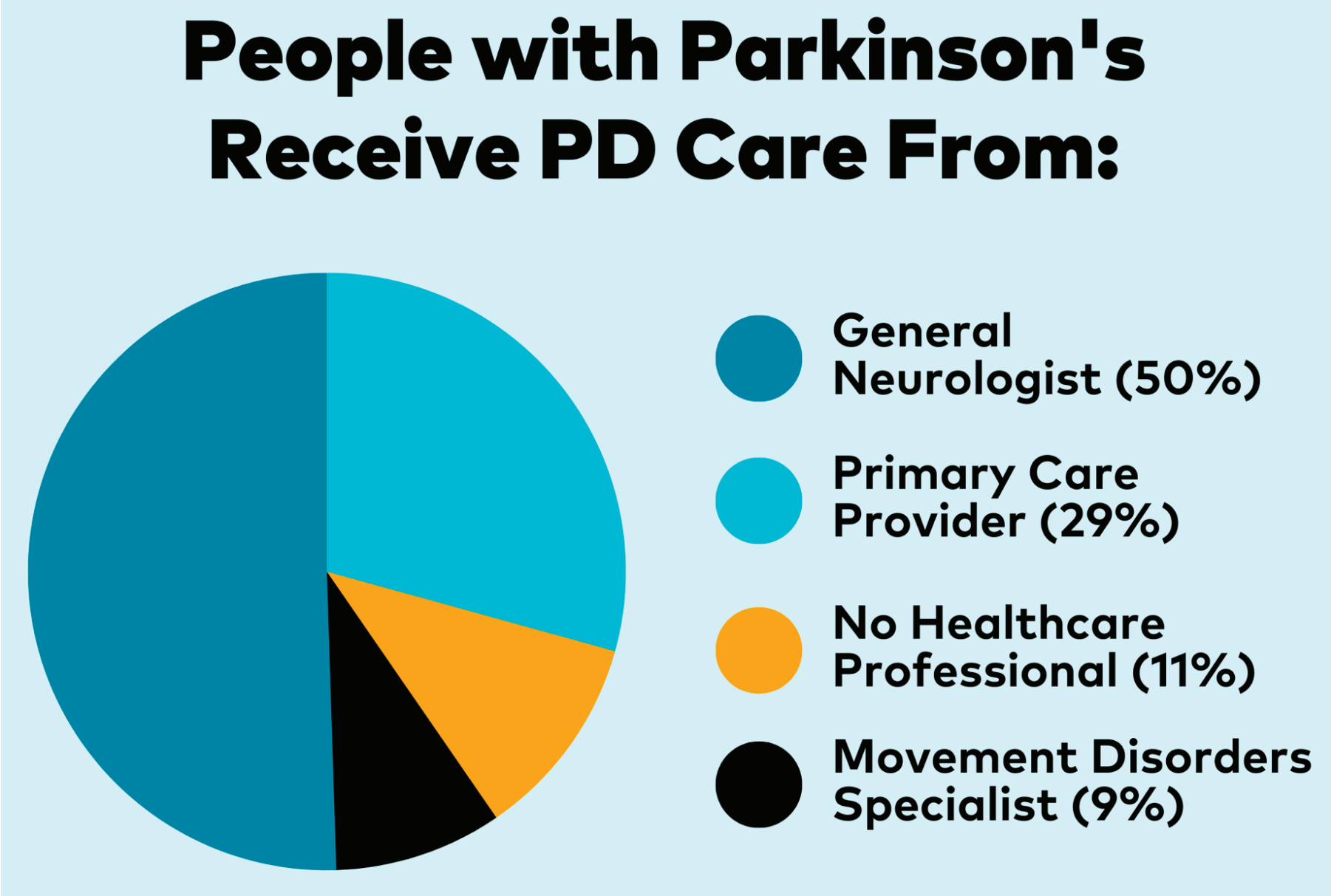
Emily Buetow[1], Erin O'Quinn[1], Andi Lipstein Fristedt[1], Sheera Rosenfeld[1]

Introduction

The U.S. faces a crisis in Parkinson's disease (PD) care. As the prevalence of PD increases with the aging population, access to quality PD care continues to erode.

- 1.1 million people living with PD in the U.S.
- 90,000 people newly diagnosed every year
- $82.2 billion national economic burden reached in 2024
- Shortage of health professionals trained in PD

People with Parkinson's Receive PD Care From:



National advocacy efforts have sparked federal action to address the crisis in Parkinson's care. 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. 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.

Methodology

To help inform the Advisory Council on PD care priorities, 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, Roundtable participants identified four high-impact national PD care solutions. **Parkinson's Care and innovation: A Patient-Centered Agenda for Change** outlines these solutions, offering a multiyear roadmap with short- and long-term actions that will drive coordinated action between key stakeholders.

- Participant Survey
- Individual Interviews
- In-Person Convening
- Agenda Drafting and Review
- Agenda Published February 2026

National Roundtable Participants

Kathy Blake, MD, MPH
Jon Blum, MPP
Tom Cassels, MPP
Morgan Daven, MA
Alessandro Di Rocco, MD
Terry Ellis, PhD, PT, FAPTA
Debbie Gunter, APRN, FNP-BC, ACHPN
Glenn Kasman, MS
Jaffar Khan, MD
John Lehr, MA
Andi Lipstein Fristedt, MPA
Sneha Mantri, MD, MS
Brian Pepin, MSEE
Cheryl Phillips, MD, AGSF
Greg Pontone, MD, MHS
Kathleen Poston, MD, MS
Carol Raphael, MPA
Cynthia Rice, MPP
Robert Stephens, MBA
Allan D. Wu, MD, FAAN

Results

The solutions identified at the Roundtable are mutually reinforcing, reflect the viewpoint of diverse stakeholders, and establish the foundation for a shared vision and coordinated action across sectors.

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).

In comparison to subspecialists, community clinicians typically have less expertise in treating PD, and thus diagnosis and care management can pose challenges. 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.

Develop a Sustainable, Integrated Care Model

that improves care coordination and patient outcomes.

Variability in resources across the U.S. poses a challenge for ensuring quality care. 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. An integrated model optimizes disease-specific outcomes, patient and care partner functional goals, and health-related quality of life over time.

Define the Minimum Clinical Dataset

to support care coordination across settings for people with PD.

Ideally, when a person with PD moves between clinical settings, their providers would be able to efficiently and securely share information. To guide shared decision-making and communicate disease impact, the PD community needs an expert consensus-driven, standardized, computable, clinically and functionally meaningful and feasible minimum dataset.

Prioritize Patient-Centered Technologies

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

A variety of tech-driven tools are now available to support people with PD, care partners, and clinicians, but uptake is still low. A framework to guide PD innovation is essential to ensure new technologies are thoughtfully designed and successfully scaled. The framework should define core principles that reflect what matters to people living with and caring for PD, support clinical decision-making, and promote financial sustainability.

Conclusion

As a national leader in Parkinson's care, the Parkinson's Foundation will play a key role in advancing these solutions in collaboration with other key stakeholders. The Foundation is committed to working across sectors to ensure every person with PD receives the highest quality care, regardless of setting. Example actions include:

- Partner with the Parkinson's Foundation Global Care Network, exploring opportunities to bridge the gap between movement disorder specialists and community clinicians.
- Provide pilot funding for clinical research on new models and approaches for care delivery through the Foundation's Innovations in Care Awards.
- Continue to lead efforts supporting initiatives that improve PD data informed by what matters most to people living with PD.
- Solicit insights directly from people with PD and care partners to guide prospective innovators and investors to develop patient-centered technology.
- Advocate at the federal and state level for legislation, regulations, and funding to improve access to quality care and address identified policy barriers.

Parkinson's Care and Innovation: A Patient-Centered Agenda for Change

To read or download the full agenda, scan this QR code or visit **Parkinson.org/Policy**

Acknowledgements

We are grateful to James Beck, PhD, Parkinson's Foundation; Abby Levy, PrimeTime Partners; Michael Okun, MD, University of Florida, Norman Fixel Institute for Neurological Disease; Peter Pronovost, MD, PhD, FCCM, University Hospitals; and John E. Duda, MD, Gretchen Glenn, LCSW, and Dawn McHale from the U.S. Department of Veterans Affairs for their contributions to the development and refinement of the solutions.

We also want to acknowledge Manatt Health for their support of the Roundtable, including expert facilitation.

[1] Parkinson's Foundation

Parkinson's Foundation

Prioritizing the Improvement of Hospital Care for People with Parkinson's Disease through the Parkinson's Foundation Hospital Care Initiative

Annie Brooks, MSW; Sheera Rosenfeld, MHS
Parkinson's Foundation

Objective

The Parkinson's Foundation (PF) Hospital Care Initiative (HCI) aims to eliminate preventable harm and promote higher reliability in care for people with Parkinson's disease (PWP) in the hospital.

Background

Annually, 1 in 6 PWP will experience avoidable complications in the hospital, often related to issues with medication management, mobility and dysphagia. The PF Hospital Care Recommendations are the foundation of the HCI and outline five Standards of Care to address these challenges.

Methods

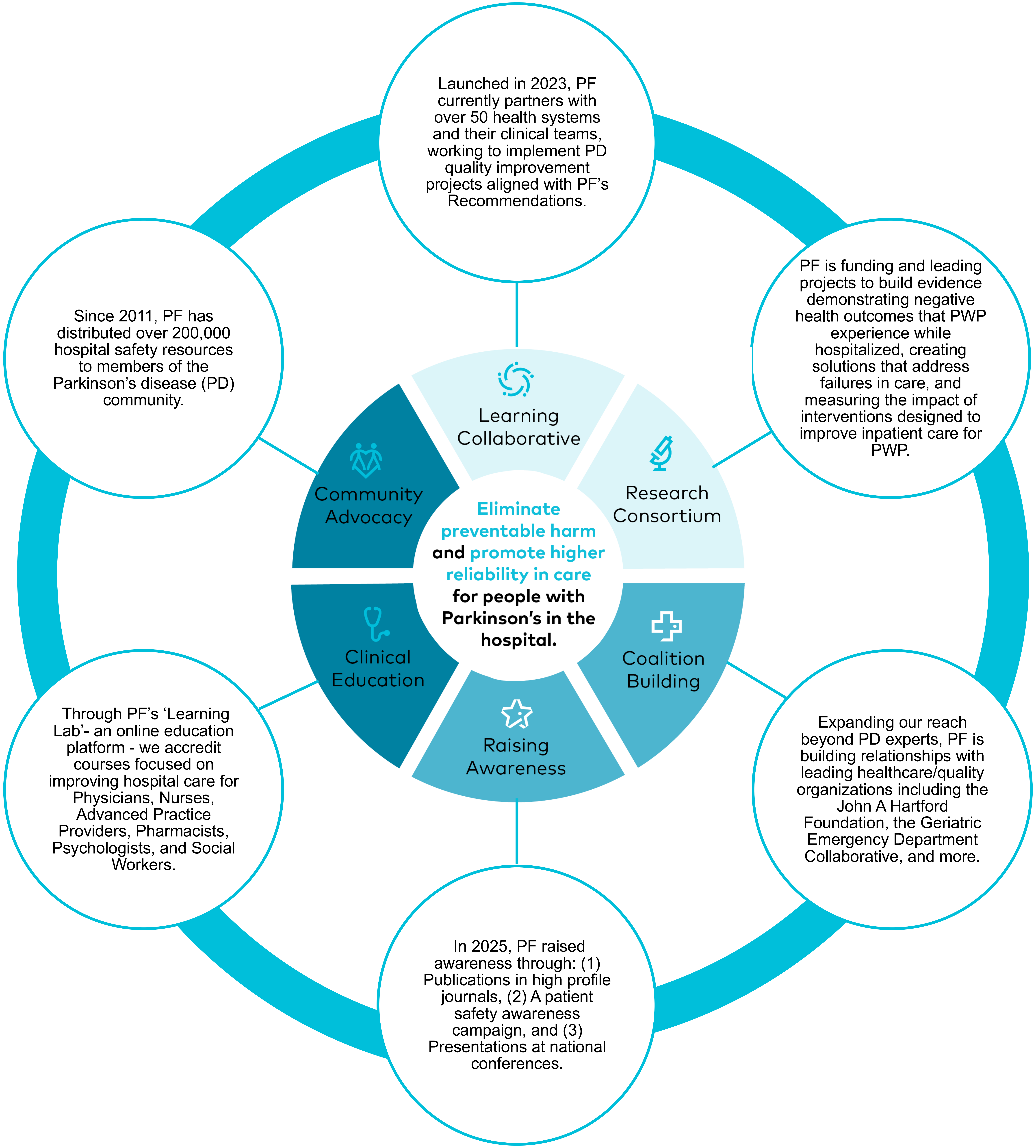
PF employs a multi-faceted strategy, bolstering our commitment to community advocacy and clinical education, broadening our reach through awareness raising and coalition building, and expanding our impact through our learning collaborative and research consortium.

Conclusion

PF invites Health Systems around the world to join our work to improve hospital care for PWP.

Acknowledgements

The Parkinson's Foundation gratefully acknowledges Ameal Pharmaceuticals for their support of our Hospital Care Initiative



Eliminate preventable harm and promote higher reliability in care for people with Parkinson's in the hospital.

Launched in 2023, PF currently partners with over 50 health systems and their clinical teams, working to implement PD quality improvement projects aligned with PF's Recommendations.

PF is funding and leading projects to build evidence demonstrating negative health outcomes that PWP experience while hospitalized, creating solutions that address failures in care, and measuring the impact of interventions designed to improve inpatient care for PWP.

Expanding our reach beyond PD experts, PF is building relationships with leading healthcare/quality organizations including the John A Hartford Foundation, the Geriatric Emergency Department Collaborative, and more.

In 2025, PF raised awareness through: (1) Publications in high profile journals, (2) A patient safety awareness campaign, and (3) Presentations at national conferences.

Through PF's 'Learning Lab'- an online education platform - we accredit courses focused on improving hospital care for Physicians, Nurses, Advanced Practice Providers, Pharmacists, Psychologists, and Social Workers.

Since 2011, PF has distributed over 200,000 hospital safety resources to members of the Parkinson's disease (PD) community.

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Optimizing Parkinson's Care: Empowering People with Parkinson's Before, During and Between Appointments

Emily Buetow, Director, Strategic Initiatives, Parkinson's Foundation
Kim Nitz, Special Projects, Clinical Affairs, Parkinson's Foundation

Introduction

For people with Parkinson's disease (PD), healthcare appointments can feel overwhelming. There is a lot to cover in a short amount of time. People with PD and clinicians report frustration with the inability to efficiently identify appointment priorities and optimize their time together.

An **optimized appointment** is one in which appointment time is used effectively by people with PD and clinicians to address:

- What is most impacting the person with PD's daily life,
- What is most time sensitive, and
- What matters most to that individual.

Providing education, training and resources to empower people with PD to become more active partners in their PD care can make healthcare visits more meaningful. By offering strategies for reflection, prioritization and confident communication of PD-related symptoms and concerns, we hope to make visits more efficient and productive for the person with PD and their healthcare team.

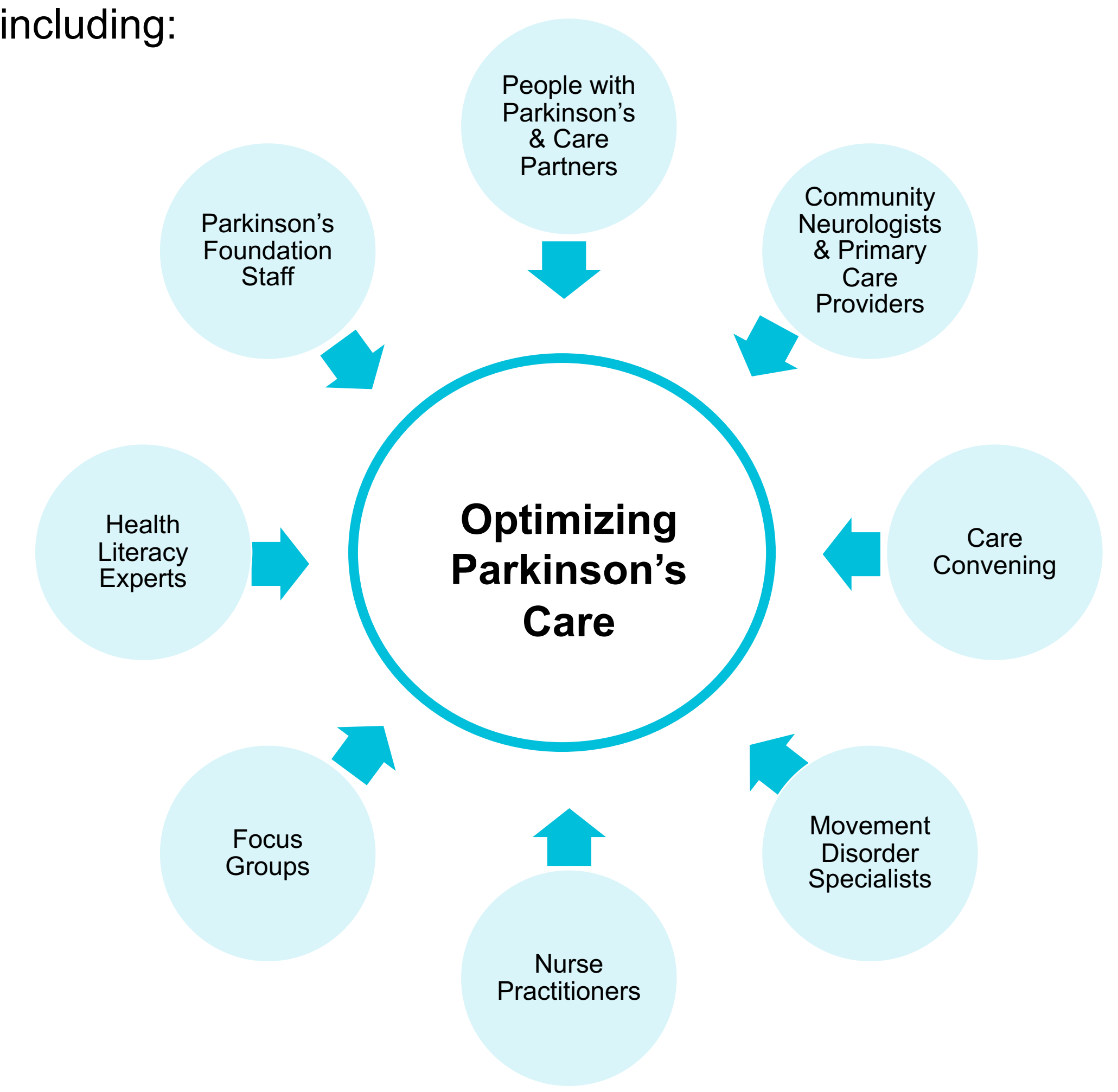
This work focuses on the importance of self-advocacy throughout the PD care cycle.

Self-advocacy is the ability to…

- ✓ Understand your needs
- ✓ Speak up for what's important to you
- ✓ Make active choices to live well

Methodology

To identify ways in which the Foundation could support people with PD in making the most of their care, the Foundation conducted a literature scan, formed a working group, hosted focus groups, and led a convening on quality care. After identifying "optimizing time spent with individuals with PD during their annual or semi-annual doctor visits" as a top priority, the Foundation conducted a landscape analysis and held recurring feedback sessions with key stakeholders, including:



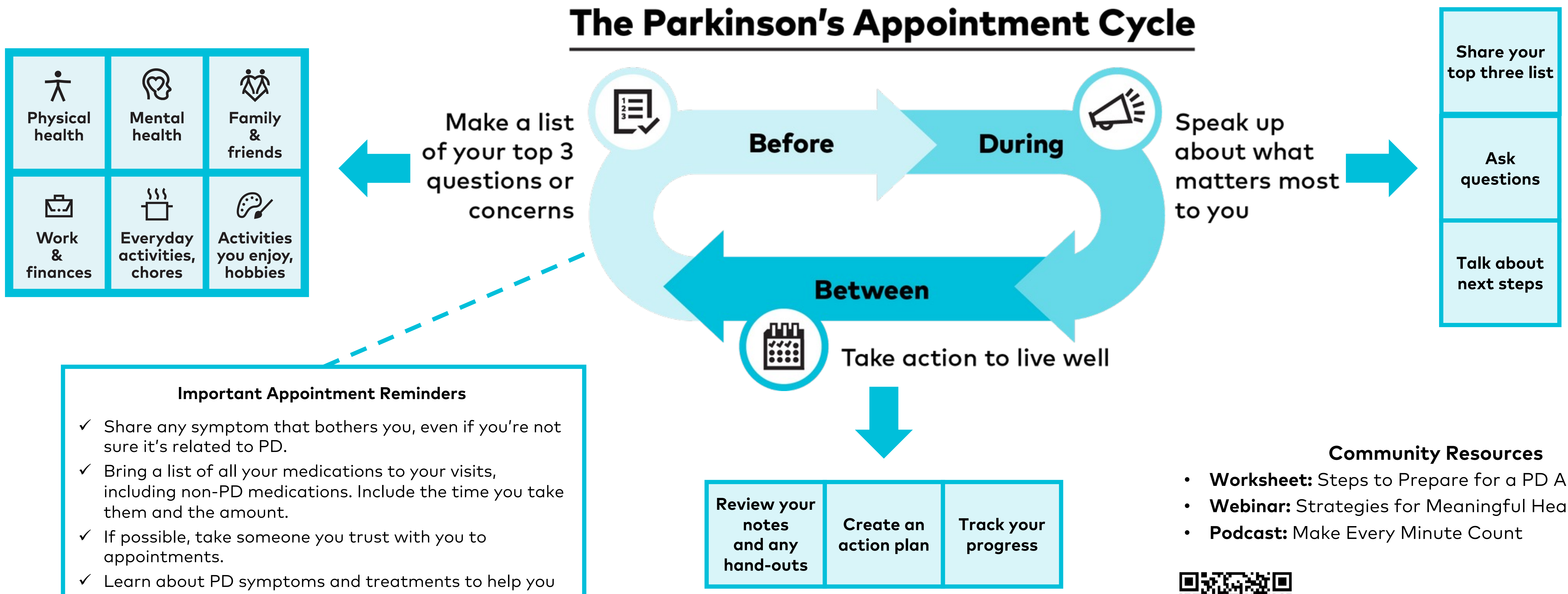
Through these methods, we identified key challenges for people with PD and clinicians during PD appointments:

1. **There is a lot to cover in a short amount of time**
   - On average, appointments are about 15 minutes, once or twice per year. There is often a lot to catch up on.
   - Parkinson's is complex, and every experience is unique. There is no one-size-fits-all approach to appointments or treatment plans.
2. **It is hard to quickly identify appointment priorities**
   - Clinicians shared the desire for people with PD to feel empowered to help direct the appointment focus, so time isn't used on low priority topics.
   - "We often spend ten minutes getting to the two minutes that matter most." - Neurologist
3. **Appointments can end without covering what matters most to people with PD.**
   - The most common unresolved needs included:
     - Answers to questions and concerns,
     - Clarity on next steps, and
     - Connections to local resources

Results

The Optimizing Care Initiative uses the PD Appointment Cycle framework to educate and empower people with PD to take an active role in their PD care before, during and between visits:

The Parkinson's Appointment Cycle



Important Appointment Reminders

- ✓ Share any symptom that bothers you, even if you're not sure it's related to PD.
- ✓ Bring a list of all your medications to your visits, including non-PD medications. Include the time you take them and the amount.
- ✓ If possible, take someone you trust with you to appointments.
- ✓ Learn about PD symptoms and treatments to help you communicate with your care team.

Community Resources

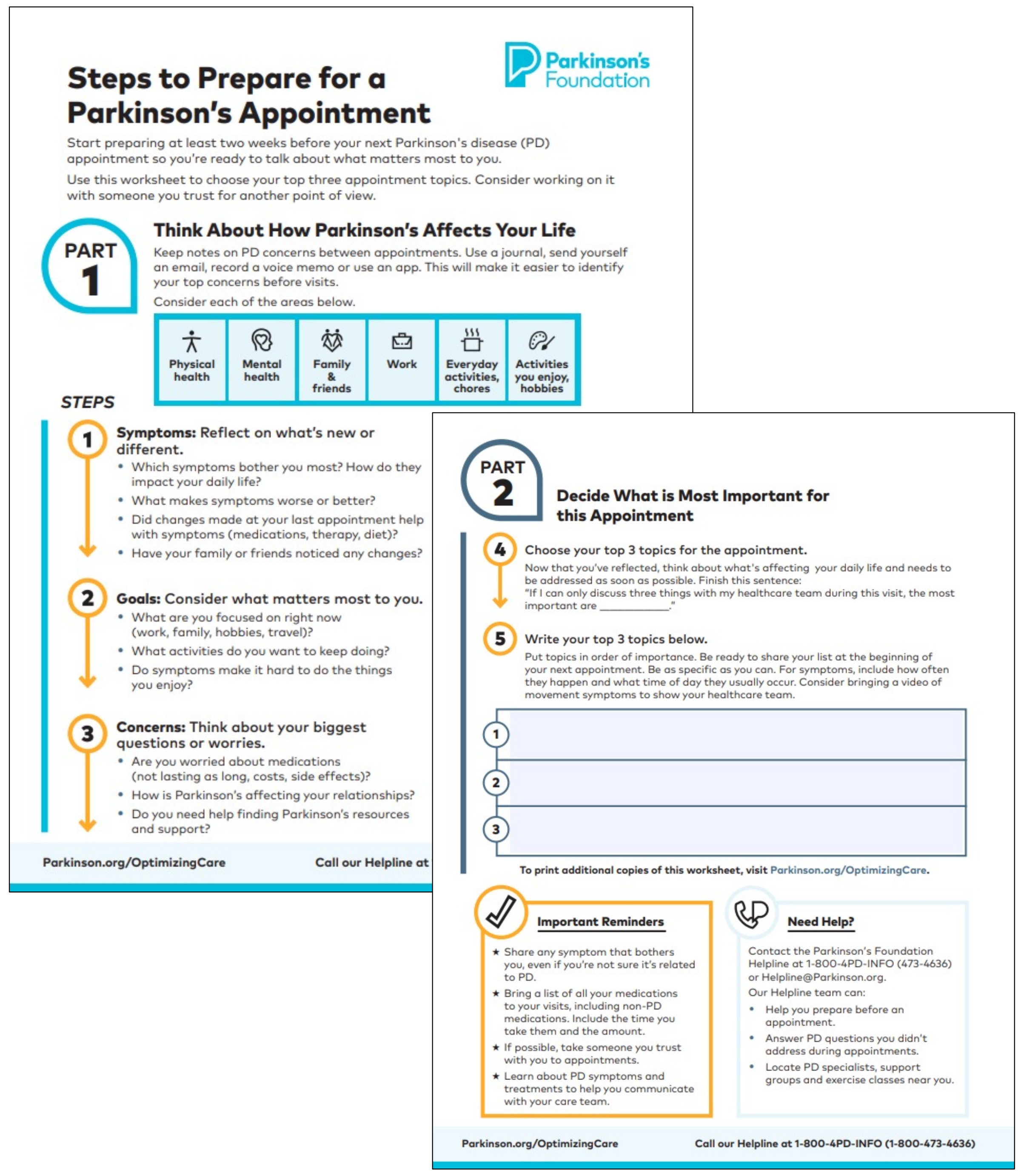
- **Worksheet:** Steps to Prepare for a PD Appointment
- **Webinar:** Strategies for Meaningful Healthcare Visits
- **Podcast:** Make Every Minute Count

To download resources & learn more, scan this QR code or visit **Parkinson.org/OptimizingCare**

Conclusion

Key Themes

- People with Parkinson's can take simple, achievable steps before, during and between appointments to make the most of their PD care.
- People with PD are experts on their experience and should think of their care as a partnership with their team.
- Self-reflection, self-education and self-advocacy are essential – and can lead to a shift in thinking and behavior.
- Parkinson's affects the whole person – focusing visits on personal priorities can be more meaningful than a narrow symptom focus.
- Bringing a companion to visits can offer many benefits. Companions should always communicate with the person with PD about their appropriate role in the appointment.



Steps to Prepare for a Parkinson's Appointment

Parkinson's Foundation

Start preparing at least two weeks before your next Parkinson's disease (PD) appointment so you're ready to talk about what matters most to you.

Use this worksheet to choose your top three appointment topics. Consider working on it with someone you trust for another point of view.

PART 1 **Think About How Parkinson's Affects Your Life**

Keep notes on PD concerns between appointments. Use a journal, send yourself an email, record a voice memo or use an app. This will make it easier to identify your top concerns before visits.

Consider each of the areas below.

STEPS

1. **Symptoms:** Reflect on what's new or different.
   - Which symptoms bother you most? How do they impact your daily life?
   - What makes symptoms worse or better?
   - Did changes made at your last appointment help with symptoms (medications, therapy, diet)?
   - Have your family or friends noticed any changes?
2. **Goals:** Consider what matters most to you.
   - What are you focused on right now (work, family, hobbies, travel)?
   - What activities do you want to keep doing?
   - Do symptoms make it hard to do the things you enjoy?
3. **Concerns:** Think about your biggest questions or worries.
   - Are you worried about medications (not lasting as long, costs, side effects)?
   - How is Parkinson's affecting your relationships?
   - Do you need help finding Parkinson's resources and support?

Parkinson.org/OptimizingCare Call our Helpline at

PART 2 **Decide What is Most Important for this Appointment**

4. Choose your top 3 topics for the appointment.
   Now that you've reflected, think about what's affecting your daily life and needs to be addressed as soon as possible. Finish this sentence: "If I can only discuss three things with my healthcare team during this visit, the most important are ___________."
5. Write your top 3 topics below.
   Put topics in order of importance. Be ready to share your list at the beginning of your next appointment. Be as specific as you can. For symptoms, include how often they happen and what time of day they usually occur. Consider bringing a video of movement symptoms to show your healthcare team.

1.
2.
3.

To print additional copies of this worksheet, visit Parkinson.org/OptimizingCare.

Important Reminders

- ★ Share any symptom that bothers you, even if you're not sure it's related to PD.
- ★ Bring a list of all your medications to your visits, including non-PD medications. Include the time you take them and the amount.
- ★ If possible, take someone you trust with you to appointments.
- ★ Learn about PD symptoms and treatments to help you communicate with your care team.

Need Help?

Contact the Parkinson's Foundation Helpline at 1-800-4PD-INFO (473-4636) or Helpline@Parkinson.org.

Our Helpline team can:

- Help you prepare before an appointment.
- Answer PD questions you didn't address during appointments.
- Locate PD specialists, support groups and exercise classes near you.

Parkinson.org/OptimizingCare Call our Helpline at 1-800-4PD-INFO (1-800-473-4636)

Acknowledgements

We are grateful to our many expert contributors, including the Parkinson Foundation People with Parkinson's Advisory Council (PPAC), community and clinician interviewees, focus group participants, Care Convening attendees and Parkinson's Foundation team members.

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COMMUNITY PARTNERS
IN PARKINSON'S CARE

COMMUNITY PARTNERS IN PARKINSON'S CARE:
A SURVEY OF CURRENT SITE CHAMPIONS IN THE PROGRAM

Rose Wichmann, Joan Gardner, Valerie Genzano, Lisa Hoffman, Cordelia Walz, Elizabeth Pollard

Background: Community Partners in Parkinson's Care is designed to educate and prepare staff in senior living communities and home care agencies to provide better care for people with Parkinson's across the United States. This program originated in the regional Upper Midwest of the United States in 2012 and was acquired by the Parkinson's Foundation in January 2023. Currently the program serves 97 partners within 27 US states. To date, this program has trained over 30,000 direct care providers. The curriculum is based on the TULIPS approach, an acronym that outlines the needs of People with Parkinson's.

A survey of site champions was conducted at Community Partner sites. Site champions serve as the primary resource for each partner site. These individuals ensure ongoing required staff training, collect program outcomes on a semi-annual basis, and maintain communication and collaboration with Community Partners program staff.

TULIPS Approach℠

Quality of
Time
Understanding
Life
Increased awareness
Pills on time
Support

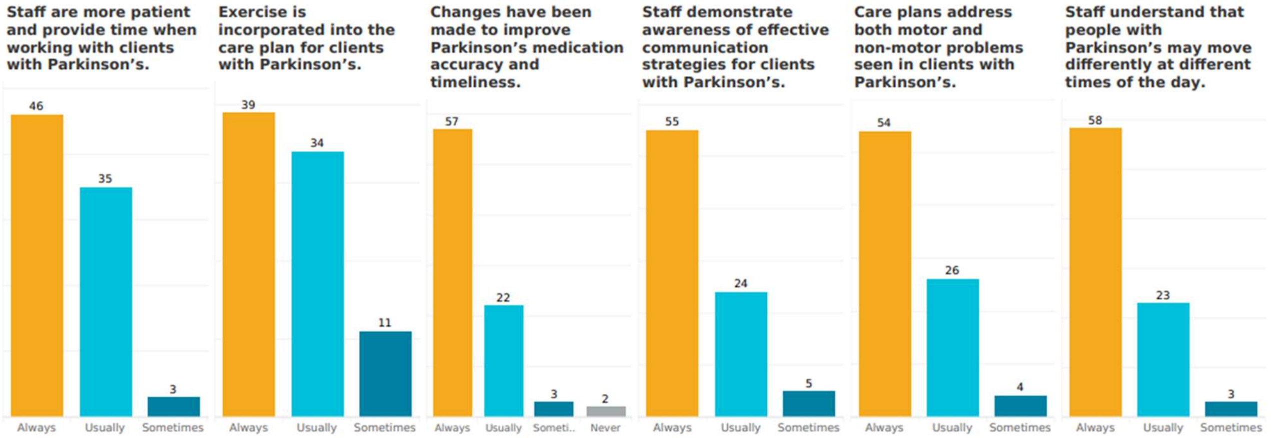
Methods: Surveys were conducted using the EthosCE webform functionality with all current site champions within the Community Partners Program. Survey results were compiled and analyzed in Tableau to review and consider future program modifications and updates.

Survey questions were focused in 3 areas on the survey:
Section 1: My role as a site champion
Section 2: Improvement in Parkinson's care at my site
Section 3: Ongoing success

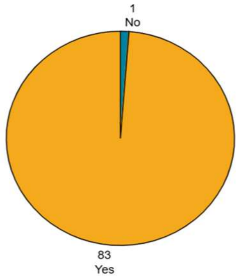
Community Partners in Parkinson's Care is grateful for the generous support of the Edmond J Safra Foundation.

Community Partners in Parkinson's Care is grateful for the generous support of Acadia Pharmaceuticals

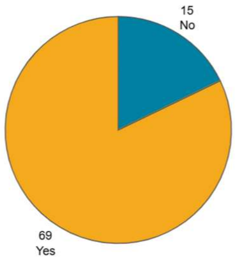
Results: Improvements in care (N=84)



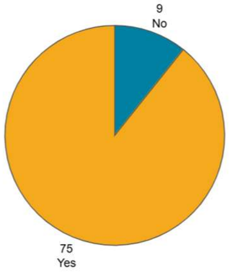
Results: This program has improved care I provide to people with Parkinson's.



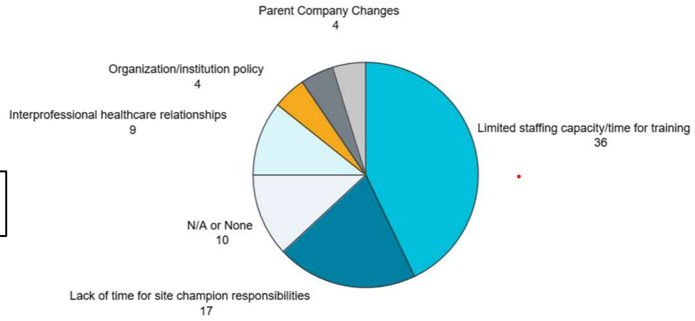
Results: I have observed staff using cueing strategies learned in this program.



Results: I feel there are more appropriate referrals to the interprofessional team.



Results: What challenges most affect ongoing success of the program?



Conclusions:

- ✓ Surveys provided positive results in site champion role and Parkinson's care improvements.
- ✓ Limited staffing and time for training were identified as the biggest challenges in ongoing success of the program.
- ✓ Survey results have been reviewed and will be used for future modifications and updates.

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Online Learning Preferences of Healthcare Providers Caring for People with Parkinson's Disease

Adrianne Smiley[1], Indhira Blackwood[1], Lisa Hoffman[1], Rebecca Miller[2], Kate Fitzgerald[3], Eli Pollard[1], Camila Gadala-Maria[1], Ashley Paul[4]

[1] Parkinson's Foundation, Miami, FL, USA, [2] Yale School of Medicine, New Haven, CT, USA, [3] Johns Hopkins University School of Medicine, Baltimore, MD, USA, [4] Johns Hopkins Medicine, Department of Neurology, Baltimore, MD, USA

Background

Continuing education (CE) is a requirement for many healthcare professionals. Yet, there is limited data on their learning preferences for online CE activities.

Objective

This study aimed to identify the learning preferences and barriers to CE participation and completion among healthcare professionals caring for people with PD.

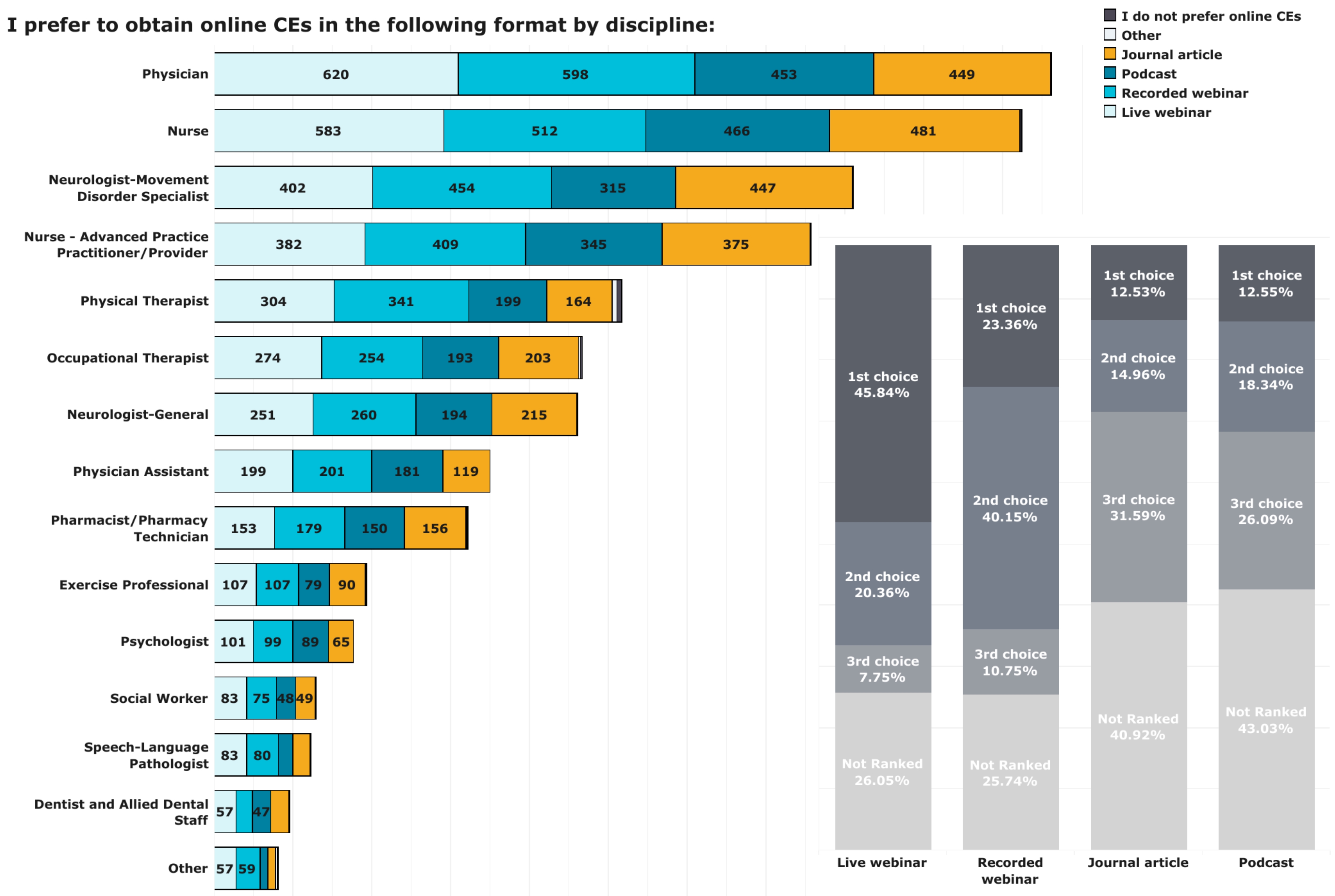
Methods and Timeline

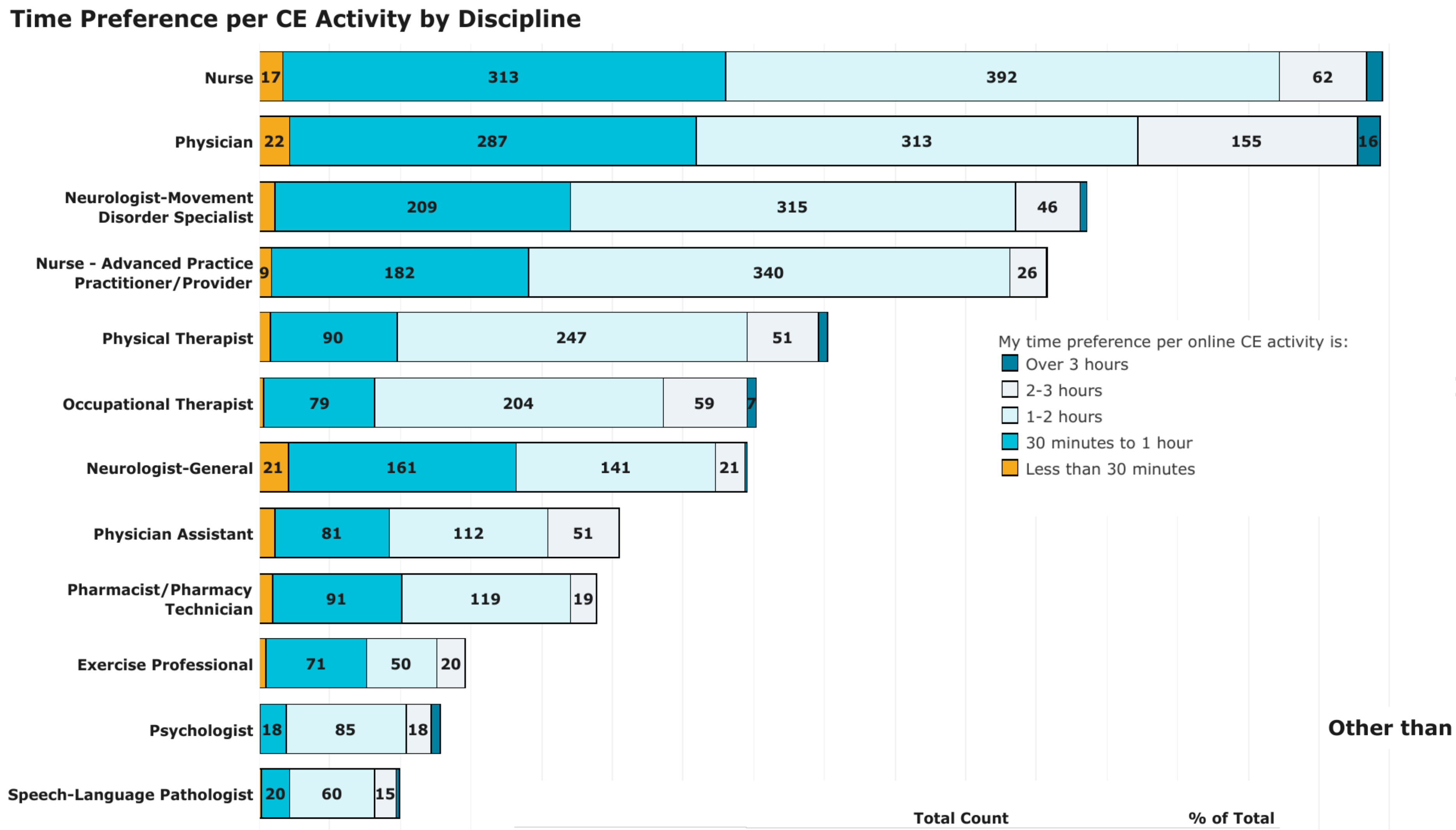
- 16-question (5 mins) online survey was developed by Parkinson's Foundation staff and healthcare professionals
- Sep 17-Oct 8, 2024: Survey open and shared with health professional networks through emails and social media.
- Descriptive statistics and regression analyses (simple & multivariable) were used to sample and examine interactions.
- Johns Hopkins University Institutional Review Board IRB00373495.

Demographics

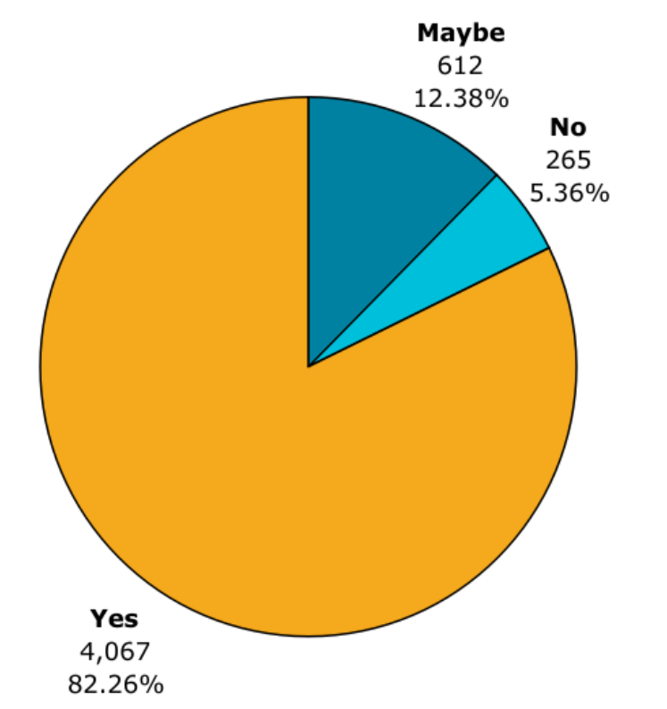
- **4,947** healthcare professionals completed the survey.
- 46% between 31–40 years old.
- 55.7% identified as women.
- 65.6% identified as White;
  21.5% as Black;
  45.7% as Hispanic/Latino.

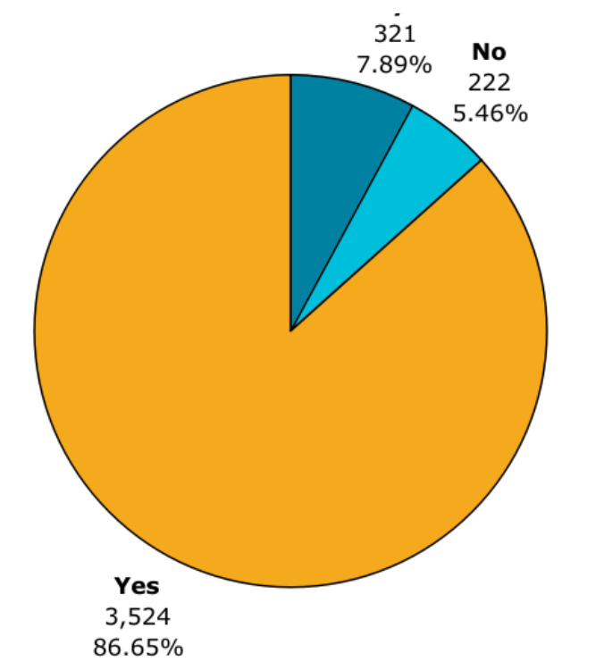
Key Findings

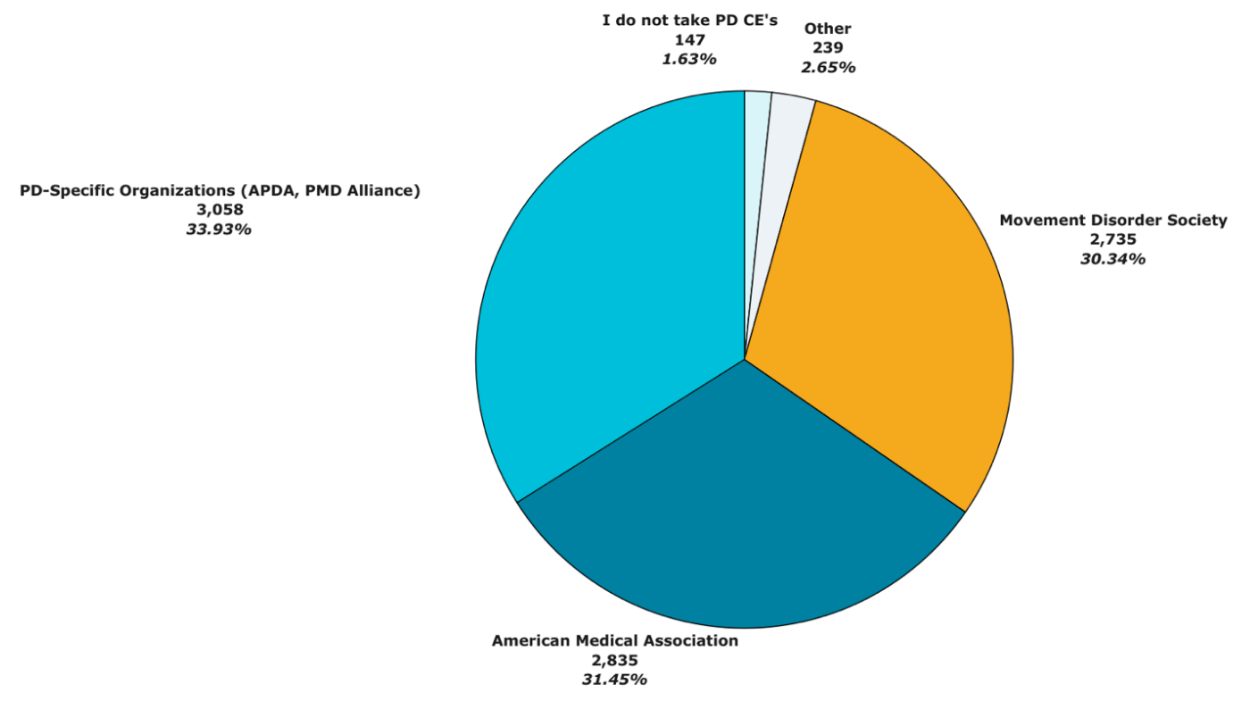

I prefer to obtain online CEs in the following format by discipline:


Time Preference per CE Activity by Discipline

	Total Count	% of Total
Less than 30 minutes	135	2.73%
30 minutes to 1 hour	1,684	34.05%
1-2 hours	2,500	50.56%
2-3 hours	565	11.43%
Over 3 hours	61	1.23%


I am aware of Parkinson's Foundation's Online CE's


I have taken a PD online CE course in the Learning Lab


Other than Parkinson's Foundation, I take my online PD CE's from the following sources:

Results

- **Format:** Live & recorded webinars are the top 2 preferred formats.
- **Preferences: (**50.5%) favored 1–2 hours course length. Relevance to practice was primary factor for CE selection (61%), interactive simulations (37.5%),case studies (36.1%)
- **Barriers to taking CE:** Time (40.1%), financial constraints (34.5%).
- **Barriers to not completing CE**: Course workload (28.5%), toggle speed of audio/video (20.2%).

Conclusion

Clinically relevant, live, interactive, and applied learning experiences are preferred learning preferences.
Time and financial constraints are barriers. Course workload and media playback speed affect completion rates. The Parkinson's Foundation seeks to implement preferences for future online CE development for healthcare professionals.