

Informing People with Parkinson's Disease of Their Gene Variant Status: PD GENERation, a North American Observational and Registry Study



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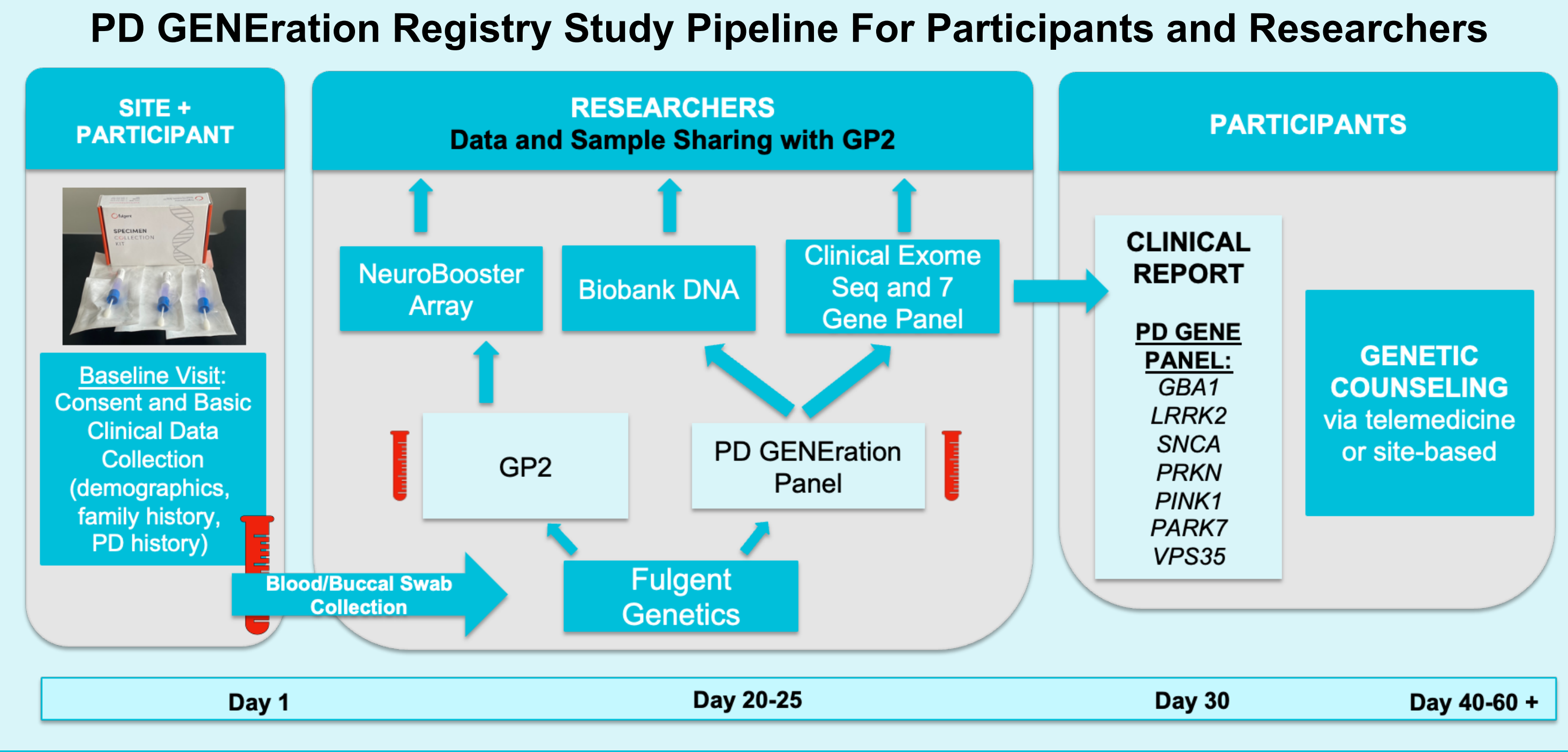
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Abstract

Objective: To describe genetic testing results of major genes for Parkinson's disease (PD) in a North American cohort as part of PD GENERation. **Background:** Although seven genes (*LRRK2*, *GBA1*, *PRKN*, *PINK1*, *SNCA*, *PARK7* and *VPS35*) are established as causative for PD, people with PD (PwP) are often unaware of their genetic status since clinical testing is rarely offered. This limits multiple opportunities, including integrating genetics into clinical care and enrolling PwP into precision medicine trials that recruit only individuals with variants. Furthermore, the yield of genetic testing to inform clinicians is not known in a large North American population. **Methods:** PD GENERation is a multi-center, observational study, offering genetic testing and counseling to those with PD in the United States, including Puerto Rico; Canada; and the Dominican Republic. DNA samples are analyzed by next-generation sequencing and deletion/duplication analysis (CLIA-certified; Fulgent Genetics). Variants classified as pathogenic/likely pathogenic and clinically actionable are disclosed. Demographic and clinical features are collected at baseline visits. **Results:** From September 2019 to January 2023 the study enrolled >7,500 participants across 35 sites and approximately 60 referral centers, with 6,328 tested. Study population characteristics were: 59% male; 90% White, 2% Asian, 2% Black/African American, 9% Hispanic/Latino; mean age of 66.4 ± 10.3 years. Sixteen percent had early-onset PD (age < 50 years), 15% were of high-risk ancestry (Ashkenazi Jewish, Spanish Basque, or North African Berber), and 22% had a first-degree relative with diagnosed PD. Of individuals tested, 842 (13.3%) had a reportable variant; 7.9% with variants in *GBA1*; 2.4% in *LRRK2*; 2.2% in *PRKN*; 0.1% in *SNCA*; and 0.1% in *VPS35*, *PINK1*, or *PARK7*. Twenty-seven (0.4%) participants had reportable variants in more than one gene. **Conclusion:** Genetic testing of well-established PD genes in this cohort resulted in a genetic diagnostic yield of 13.3%, overall, and, notably, 9.2%, in those unsuspected of harboring variants. Together with the increasing utility of self-knowledge of PD gene status, the findings support a shift to offering universal genetic testing to PwP. ****The PD GENERation data shown below is an update as of June 1st, 2023****

Methodology

PD GENERation is a multi-center, observational study, offering genetic testing and counseling to those with PD in the United States, including Puerto Rico; Canada; and the Dominican Republic. DNA samples are analyzed by next-generation sequencing and deletion/duplication analysis (CLIA-certified; Fulgent Genetics). Variants classified as pathogenic/likely pathogenic and clinically actionable are disclosed.



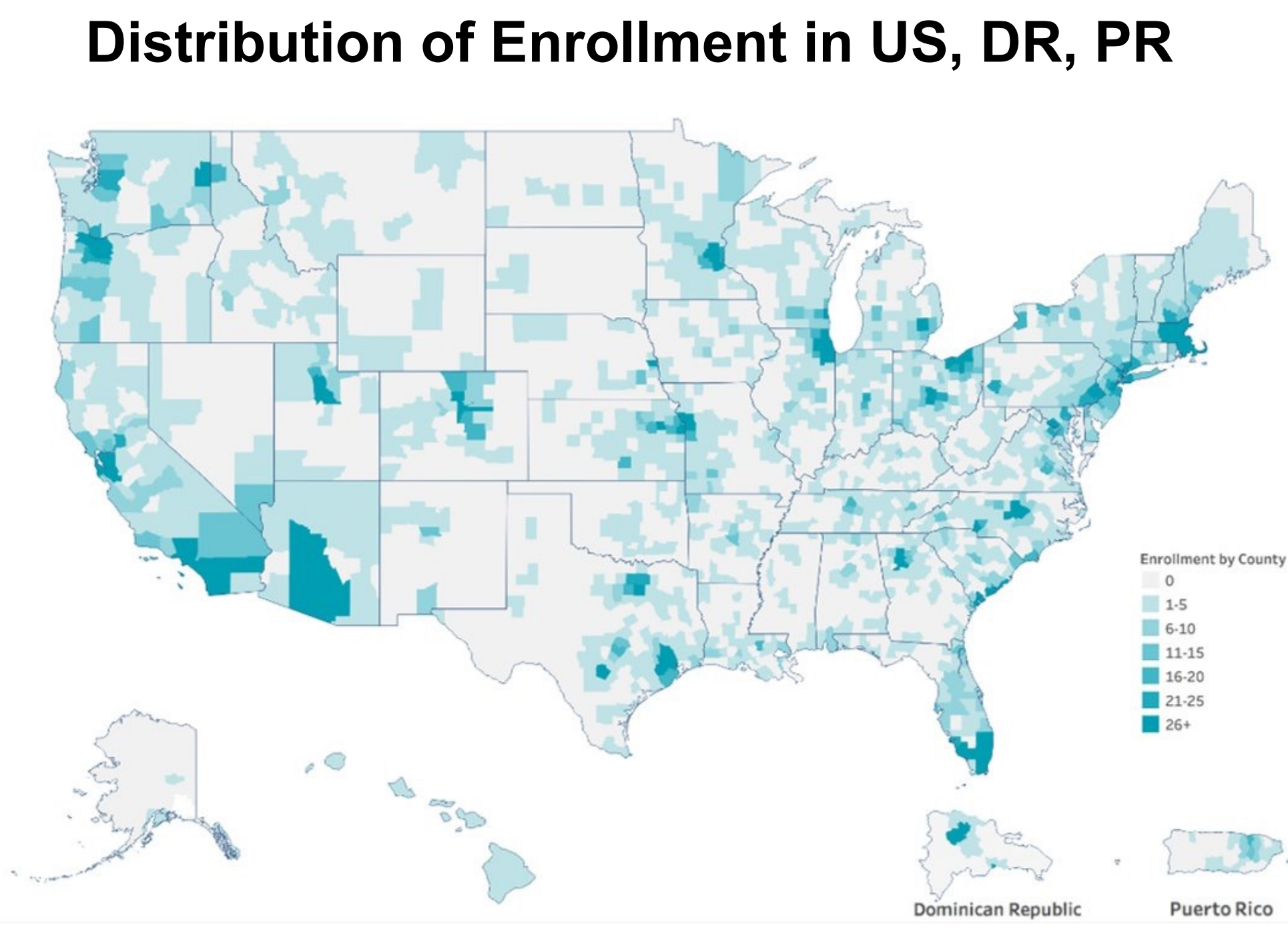
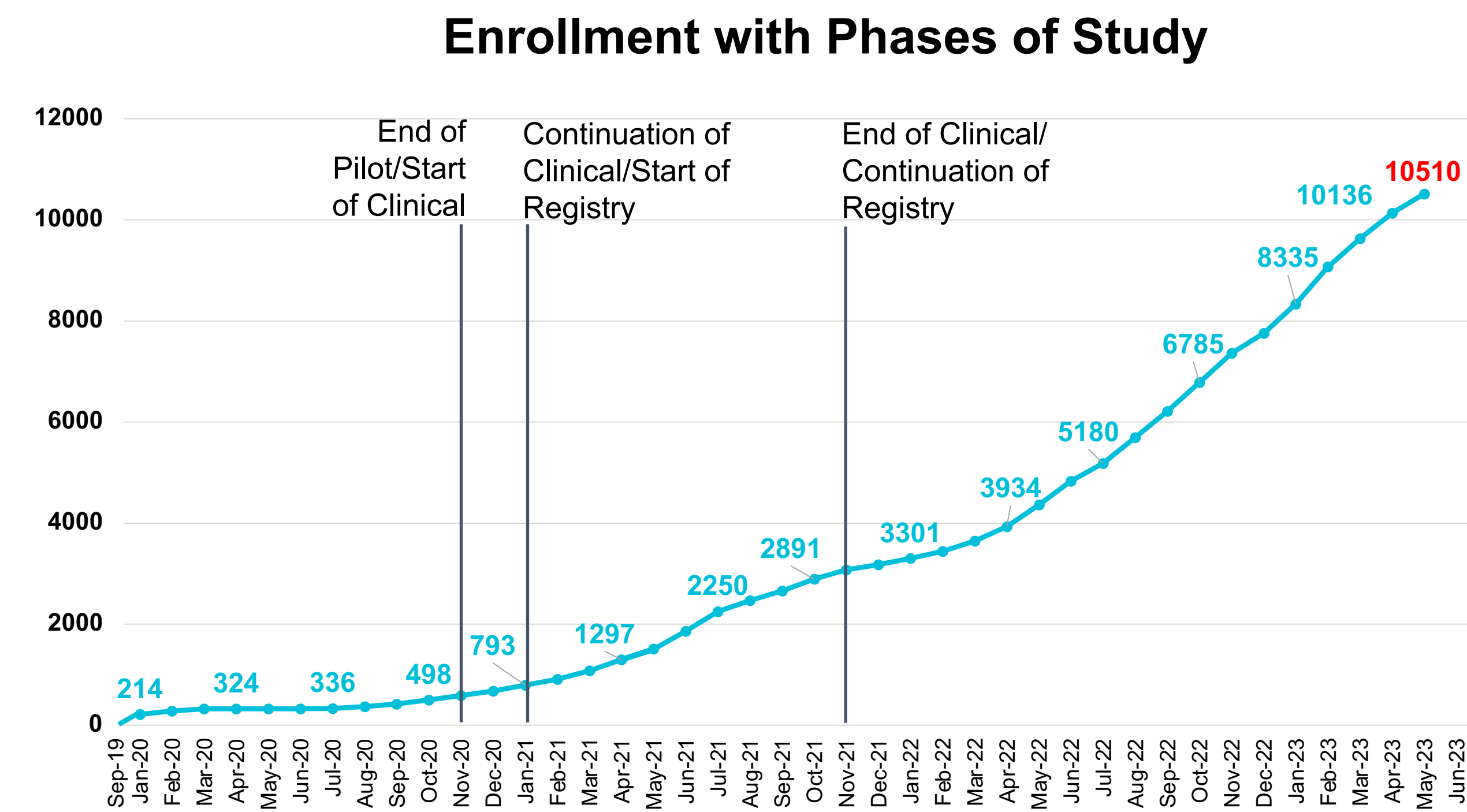
- Three phases of PD GENERation:**
- 1) **Pilot study**- launched in Sept. 2019 and aimed at feasibility
 - 2) **Clinical study**- launched in Nov. 2020- continuation of the Pilot study at a larger scale, aimed at frequency and characterization of clinical phenotypes
 - 3) **Registry study**- launched in Jan. 2021 and aims to make genetic counseling and testing accessible to 15,000 participants

Results

All results below are as of June 1, 2023. The PD GENERation study has enrolled 10,510 participants.

Study Enrollment Per Country

- United States (US): **10,112**
- Puerto Rico (PR): **33**
- Dominican Republic (DR): **305**
- Canada: **60**

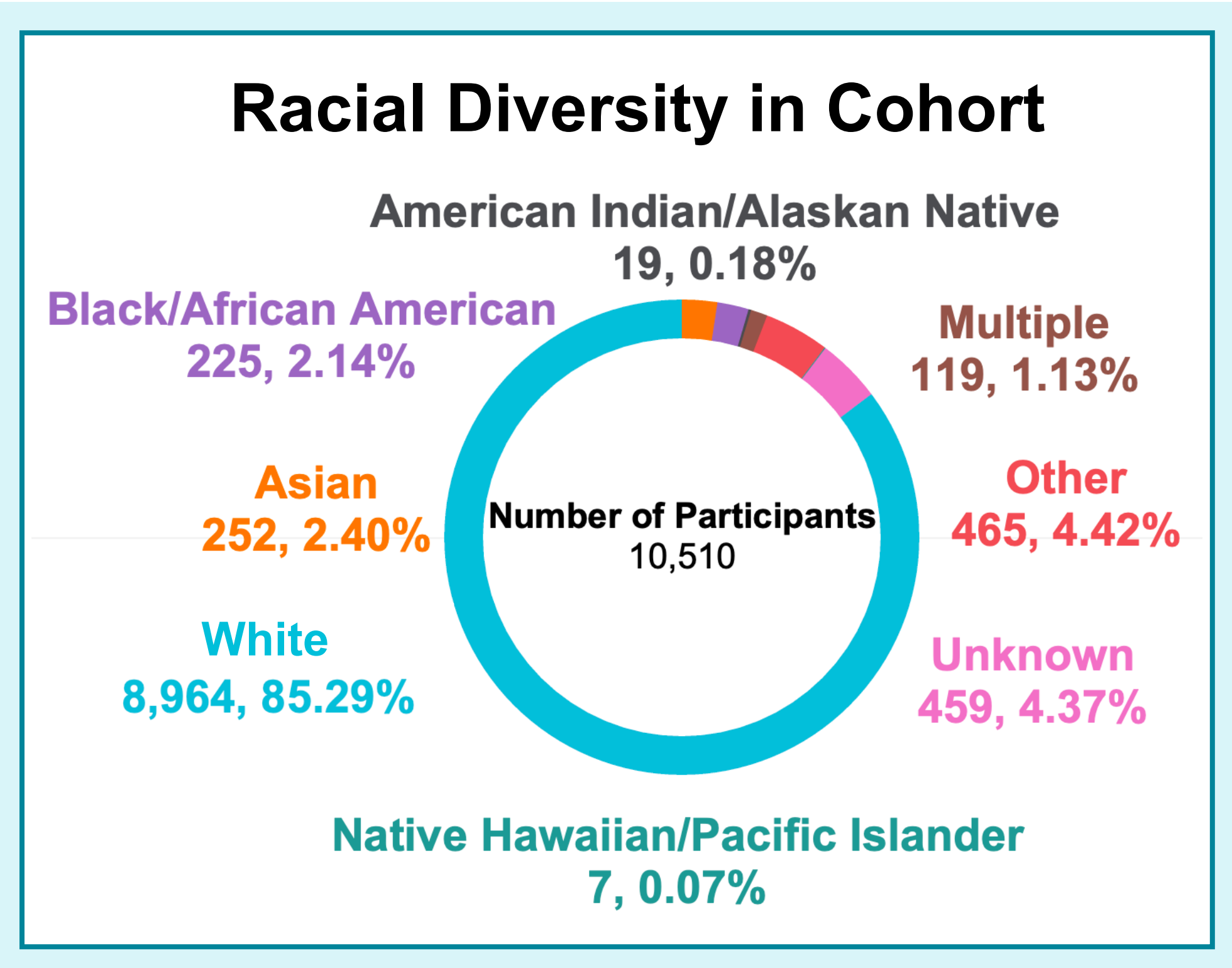
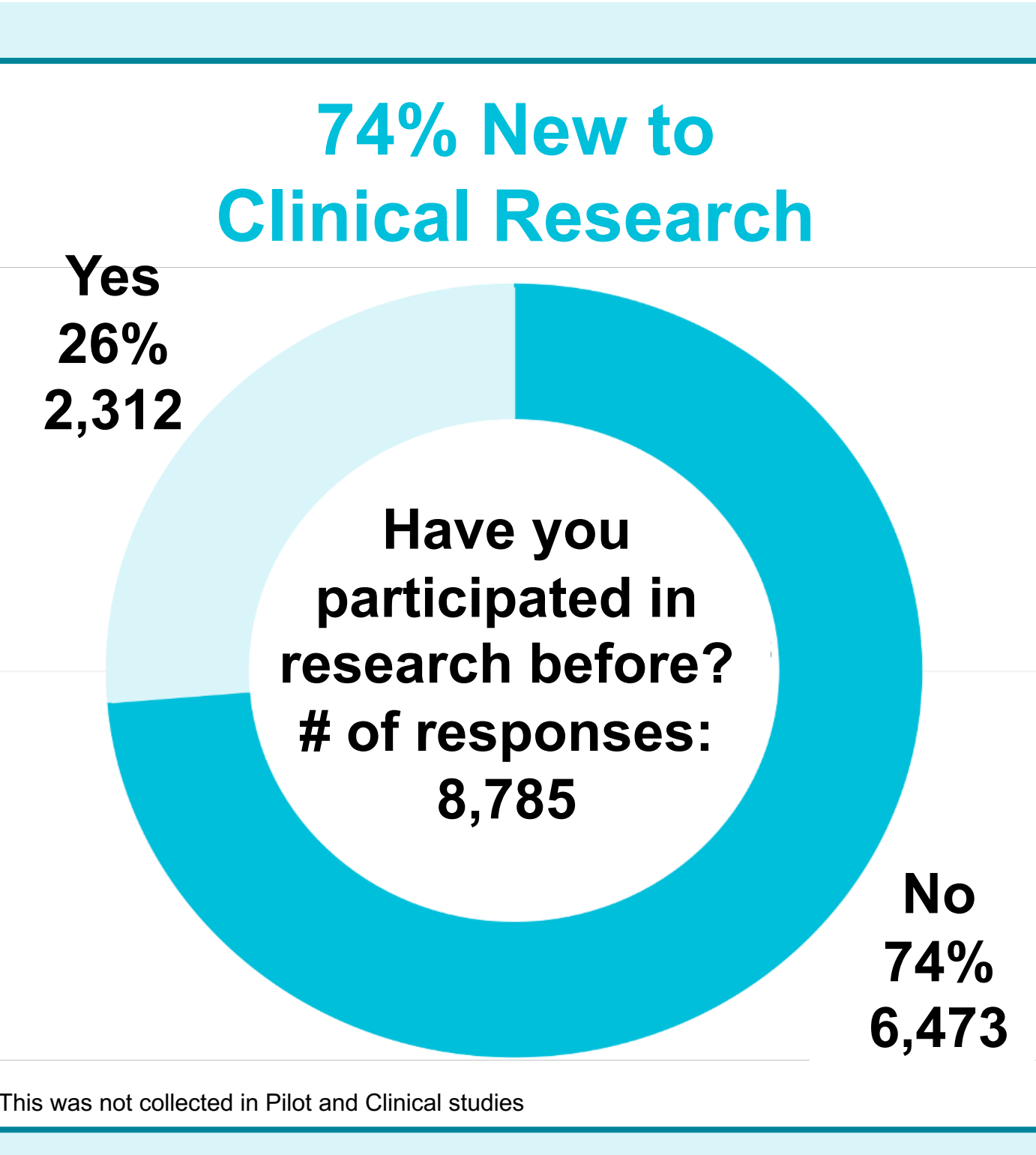


58%:42% genetic sex of Male:Female

69 years average age at enrollment

62 years average age at diagnosis

58% diagnosed in the last 5 years



Hispanic Participants
1,009 Participants
10.1% Overall

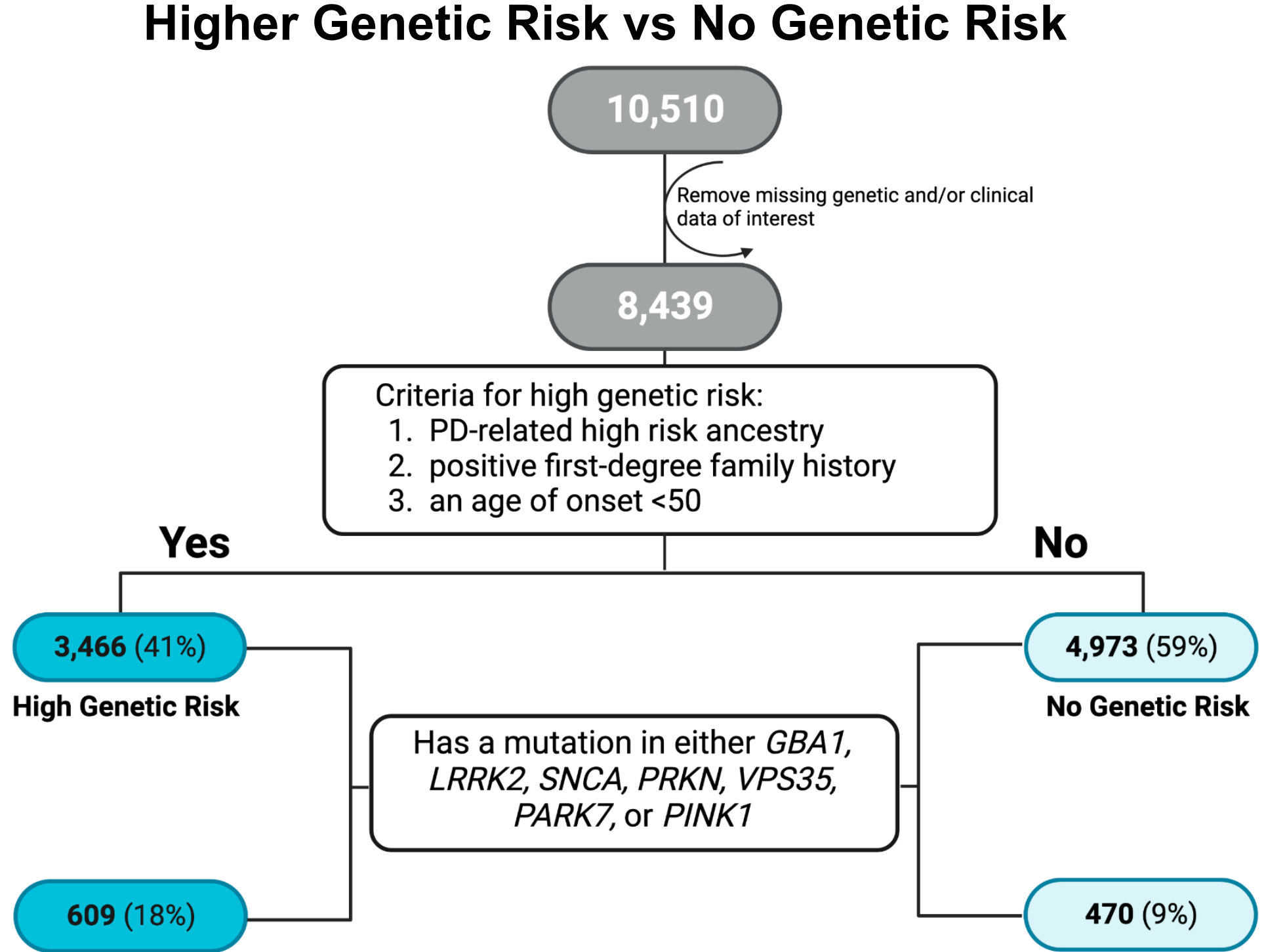
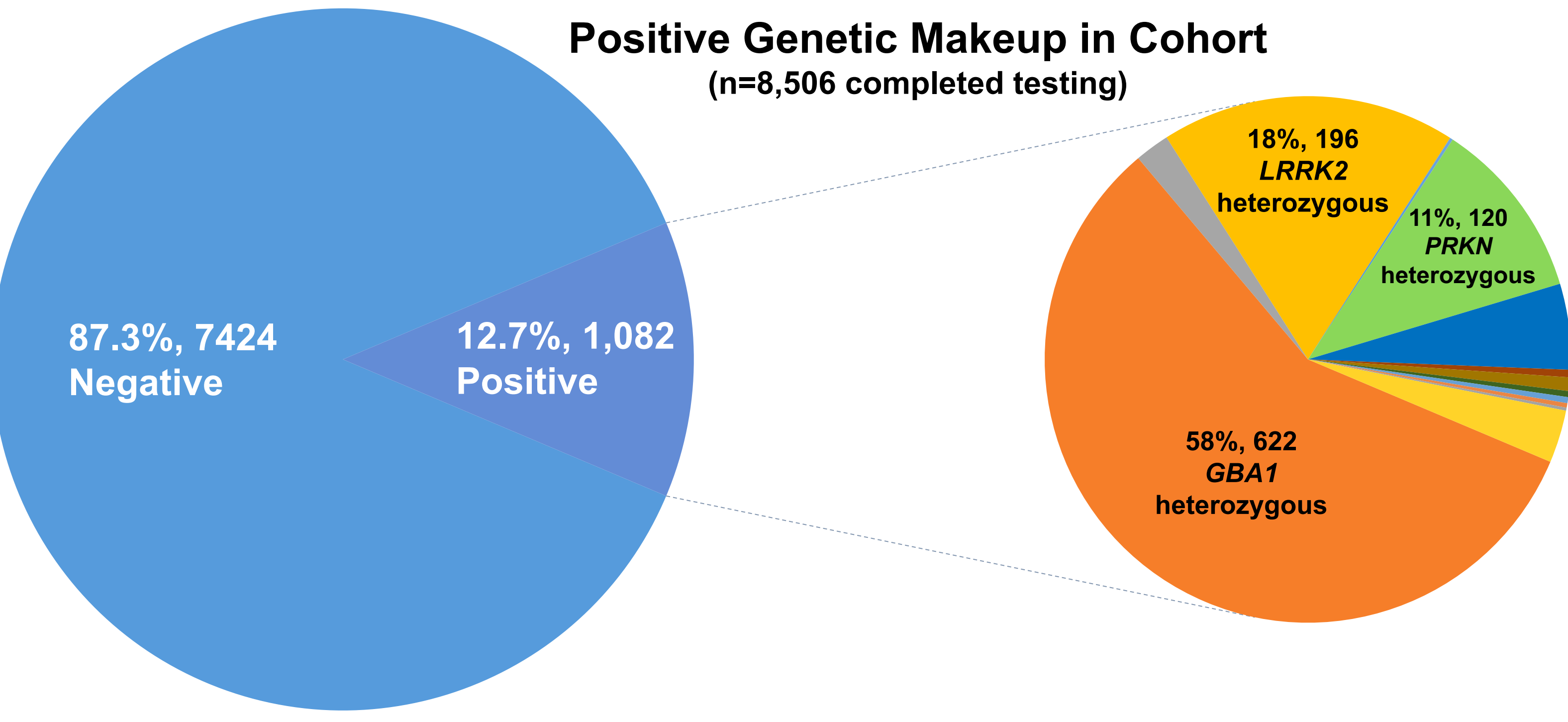
PD GENERation: Trazando el futuro de la enfermedad de Parkinson. Ayúdenos a cambiar el curso de la enfermedad de Parkinson.

Black and African American Participants
225 Participants
2.1% Overall

PD GENERation: Mapping the Future of Parkinson's Disease. Help us change the course of Parkinson's.

15 Seminars, webinars, and in-person educational events have taken place in one year.

- No Mutation (n=7424)
- GBA Heterozygous (n=622)
- GBA with two mutations or more (n=23)
- LRRK2 Heterozygous (n=196)
- LRRK2 with two mutations or more (n=2)
- PRKN Heterozygous (n=120)
- PRKN with two mutations or more (n=57)
- VPS35 Heterozygous (n=5)
- VPS35 with two mutations or more (n=0)
- SNCA Heterozygous (n=9)
- SNCA with two mutations or more (n=0)
- PINK1 Heterozygous (n=4)
- PINK1 with two mutations or more (n=4)
- PARK7 Heterozygous (n=3)
- PARK7 with two mutations or more (n=2)
- Carrier in multiple mutations (n=35)



Conclusion

PD GENERation makes genetic testing and counseling accessible for PwP and their clinicians. The Parkinson's Foundation plans to continue to recruit beyond 15,000 participants based on the needs of the patient and research community. By "opening the door" for genetic testing to all those interested and from all backgrounds, the study helps inform care, diversify the data, engage people in research, and qualify more for enrollment in precision medicine clinical trials for PD. Data generated from this study will be openly accessible to the research community.

For more information on the PD GENERation study, please scan the QR Code.





Systematic Screening and Treatment of Depression in Parkinson's Disease within Movement Disorders Centers: A Quality Improvement Initiative

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OBJECTIVE

To assess the feasibility and impact of systematic depression screening and management in movement disorders centers.

BACKGROUND

- Depression is common in Parkinson's disease (PD) and has a significant adverse impact on quality of life.
- A survey of clinicians at Parkinson's Foundation Centers of Excellence (PF COEs) revealed that most centers do not systematically screen for depression, and that the use of mental health professionals and antidepressants varies substantially, suggesting that clinical practice changes could improve care.

METHODS

Fig. 1 Study Overview

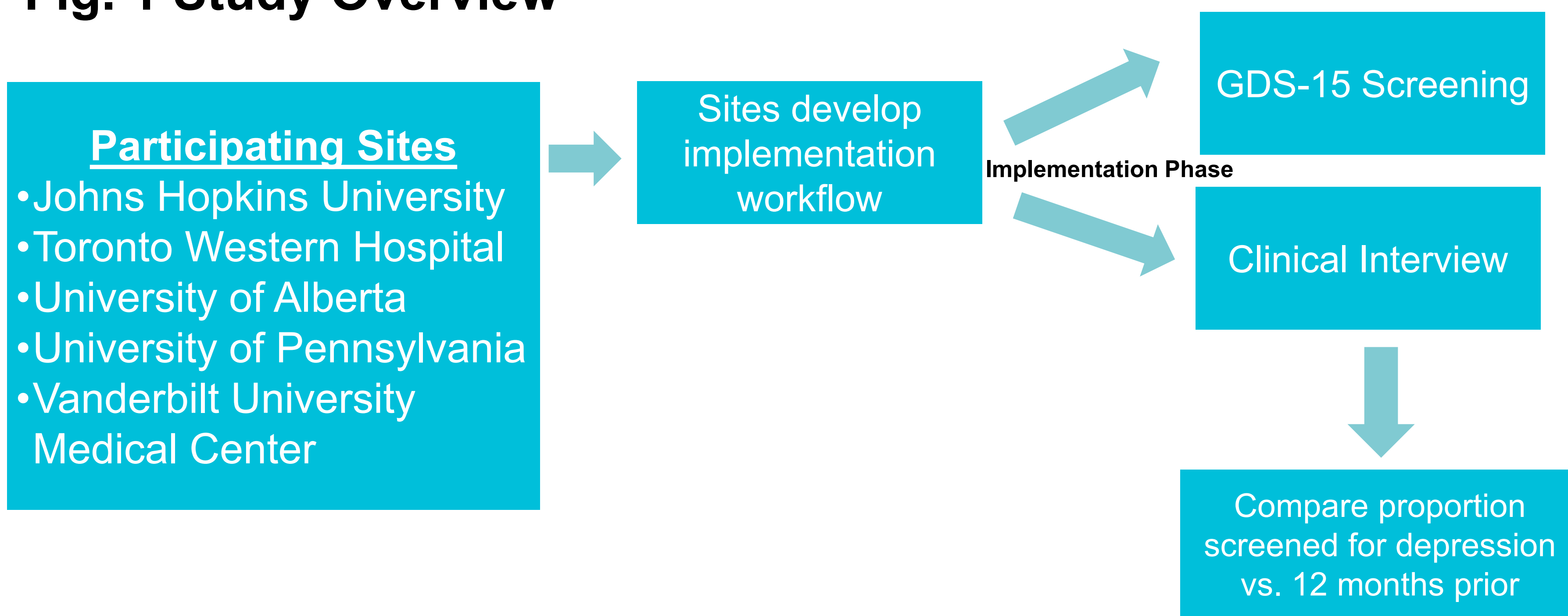
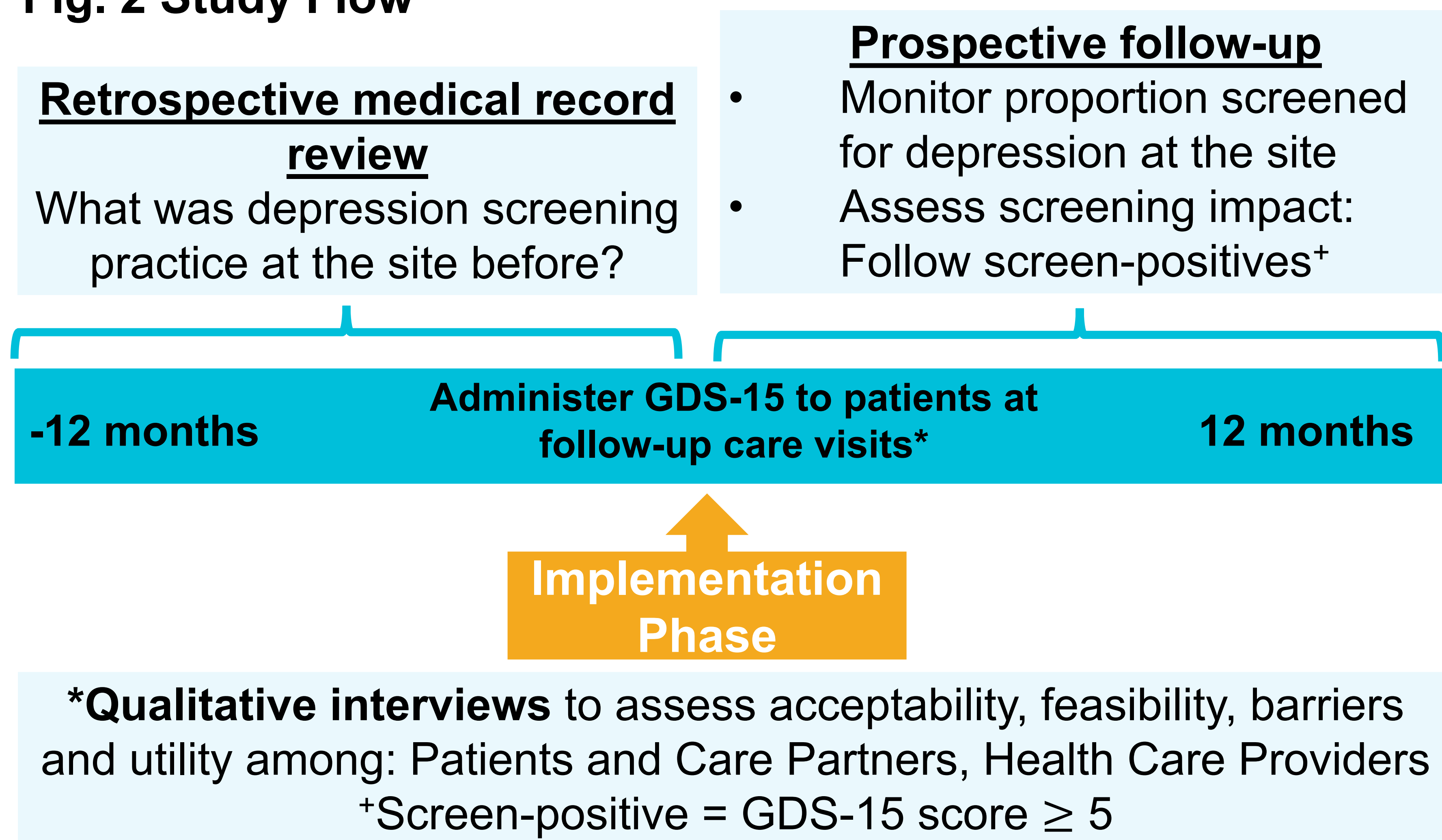


Fig. 2 Study Flow



RESULTS

Retrospective review of depression screening

310 patients seen by 29 HCPs in the year prior to the implementation of systematic screening were reviewed.

Prior to implementation of formal GDS-15 screening:

- ~76% (range 56-100%) of patients were screened.
- **Only 12%** screened (range 0-57%) with a formal depression instrument.
- Instruments used other than the GDS-15: the Patient Health Questionnaire-2, MDS-Unified Parkinson's Disease Rating Scale, Non-motor Symptoms Questionnaire, the Beck Depression Inventory, and the Beck Depression Inventory Fast Screen.

Implementation Phase

- 1,036 patients (~68%, range 54-84%, out of all patients seen clinically), were screened using the GDS-15 across the 5 sites.
- 378 (36%) of patients screened positive for depression.
- 65% of health care providers reported that screening led to a change in clinical management for at least 25% of participants.

Fig. 3 Preferred Depression Screening Implementation Methods Across Sites



Barriers to formal screening

Among 584 patients who were not formally screened with the GDS-15 the most common barriers include:

- Insufficient time completing questionnaire in advance, waiting room, during visit (n=223, 38%)
- No EHR/EMR or internet access (n=162, 28%)
- Insufficient staff time (n=138, 24%).

Prospective Follow-up (July 2021 – June 2023)

Fig. 4 Depression treatment among screen-positives (GDS ≥ 5)

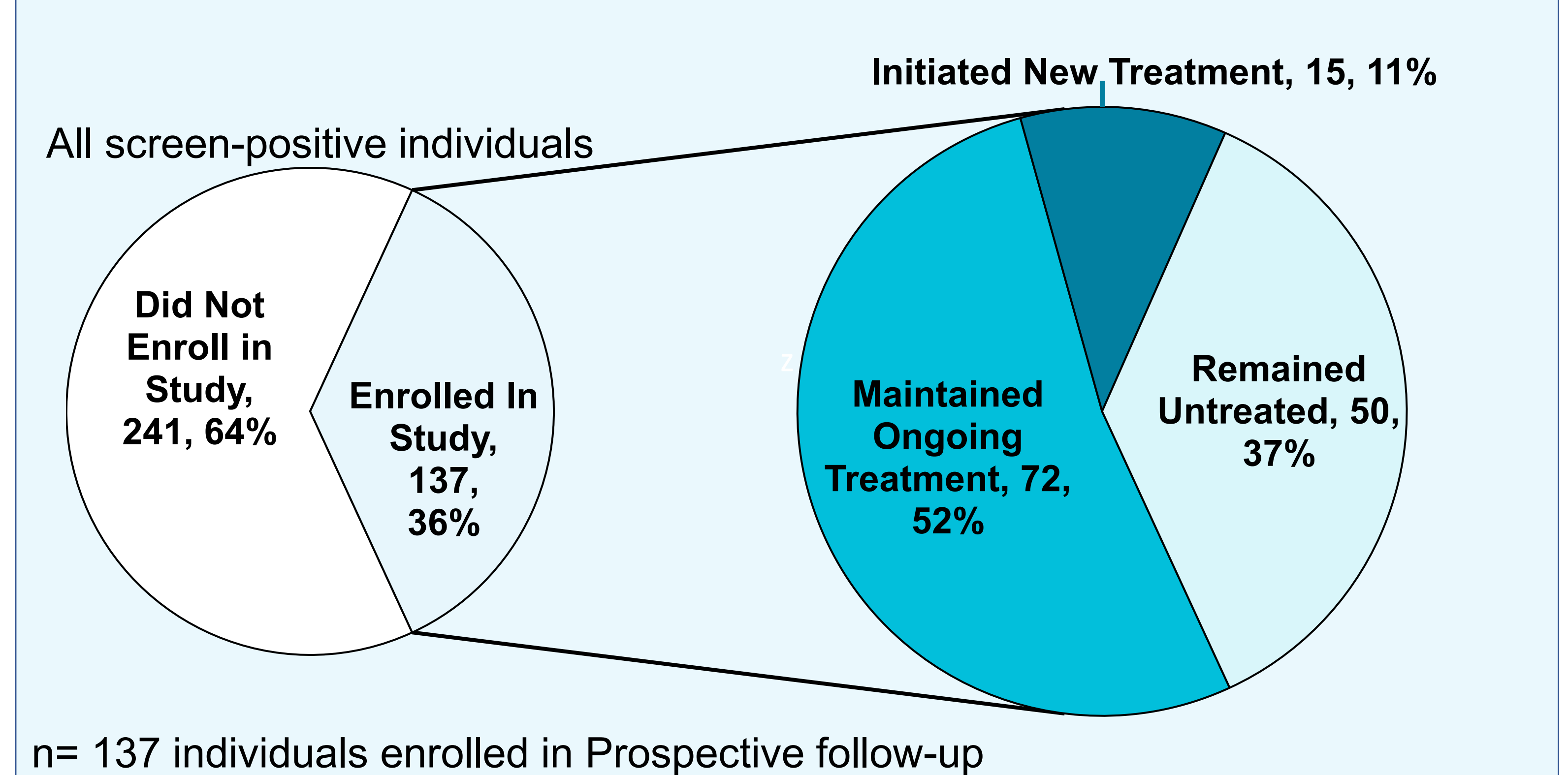


Table 1: Change in GDS-15 and PDQ-39 scores among screen-positive cases

	Baseline (n=137)	6 months (n=133)	12 months (n=121)	Change Month 6 vs. Baseline	Change Month 12 vs. Baseline
GDS-15 (mean, sd)	9.0 ± 3.7	7.5 ± 3.7	6.8 ± 3.3	-1.5 ± 0 ^a	-1.9 ± 4.4 ^b
PDQ-39 (mean, sd)	36.4 ± 15.2	35.7 ± 15.5	34.0 ± 14.0	-0.7 ± 0.3 ^c	-1.3 ± 10.6 ^d

^ap<0.001; ^bp<0.0001; ^cp = 0.93; ^dp = 0.13 (paired t-tests)

CONCLUSION

- Implementation of systematic screening using the GDS-15 is feasible among Parkinson's Foundation Centers of Excellence.
- Time required is a barrier to formal screening.
- 77% recommended the screening program be implemented at other PF Centers of Excellence.
- Sites adopted GDS-15 administration based on practice practicalities during the COVID-19 pandemic, substantially increasing the number of patients screened using a formal instrument.
- While overall quality of life measures did not change over 12 months, significant changes in GDS-15 scores were observed, suggesting improvements in depressive symptoms.

ACKNOWLEDGEMENTS

Special acknowledgement to site investigators: Thomas Davis, MD and Amy Brown, MD (Vanderbilt University); Nabila Dahodwala, MD (University of Pennsylvania); Connie Marras, MD, PhD (Toronto Western Hospital); Kelly Mills, MD (Johns Hopkins University); Janis Miyasaki, MD (University of Alberta).

Understanding Parkinson's Disease Patients' and Carepartners' Palliative Care Knowledge & Preferences

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Introduction

People with Parkinson's (PWP) and care partners (CP) have significant palliative care (PC) needs, however little is known about their preferences and knowledge of PC. There is sufficient support for implementing PC as a new standard of care for PWP and CP. As part of a national project on implementing outpatient PC in Parkinson's Foundation Centers of Excellence (COE) we operationalized PC as the assessment and management of:

1. Non-motor symptoms
2. Patient grief/emotional/spiritual needs
3. CP needs
4. Completion of annual advance care planning (ACP)
5. Timely referrals to specialist PC and hospice

Objective

To understand patient and family perceptions and knowledge of PC.

Methods

Using a qualitative descriptive design, we completed semi-structured interviews with PWP and CP (n=47- 23 PWP; 24 CP) recruited from 15 COE. All interviews were audio-recorded, de-identified, and transcribed. Data were coded and 5 themes were identified.

Results

Table 1. Demographics of Patients and Care Partners

	People Living w/ PD (n=23)	Care Partners (n=24)
Age, mean (SD)	69.5 (8.14) years	68.88 (9.93) years
Years of PD symptoms, mean (SD)	13.73 (9.03) years	
Years of additional household responsibilities		6.04 (5.65) years
Gender (female)	26.09% (17)	70.83% (17)
Hispanic/Latino (No)	95.65% (22)	95.83% (23)
Race		
White	78.26% (18)	91.67% (22)
Non-white	26.09% (6)	8.33% (2)
Married	82.61% (19)	87.50% (21)
Other relationship status	17.39% (4)	12.5% (3)

Acknowledgements

We thank our Patient & Care Partner advisory council for their input on the interview questions.

This project is through a Patient-Centered Outcomes Research Institute® (PCORI®) [Dissemination and Implementation Award # DI-2019C2-17499]. The views, statements, and opinions in this poster are solely the responsibility of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee.

Results Cont.

PWP and CP wanted more education and support to address their PC needs. The following themes related to the 5 PC components were identified.

Table 2. Themes and Illustrative Quotes

<p>Theme 1: It's the non-motor stuff that is driving everyone crazy.</p> <p>Martha Patient: I'm impressed that [the new Neurologist] even asked me about bowel and bladder problems and things like how the medications work on my stomach and if I'm havin'...a lot of sweating, and she's talked to me about my drooling and my speech. I like that she's very holistic in her approach.</p> <p>Jennifer Care Partner: Can we stop calling this movement disorder because it's the non-motor stuff that drives everybody crazy. Let's give it another name.</p>
<p>Theme 2: "It's the caring, connection part that is missing"</p> <p>Mary Patient: He [Neurologist] said, "I think you're depressed" ...I don't think I'm depressed. I think I'm sad... I'm trying everything I can to feel better.</p> <p>Cynthia Care Partner: They're an excellent [clinic],...they know about Parkinson's, and they have excellent advice. It's just...the caring part,...the connection part...it just sort of feel like... you're a number and you're kinda going through, and...then they're onto the next one.</p>
<p>Theme 3: Care partners want more education, guidance, and coping skills</p> <p>William Patient: But they're [carepartners] also human beings. They will have moments of doubt. They will...be overwhelmed. It's kind of unfair to them.</p> <p>Stephanie Care Partner: They (doctors) said that I have to take my—care of myself. I said, "I know, but how?"</p>
<p>Theme 4: Advance care planning conversations need to happen over time.</p> <p>Dorothy Patient: I don't think we've planned much...I'd like to have somebody sit down and say, "What do you think...to answer some questions...but I don't have anybody to talk to about that.</p> <p>Andrew Care Partner: It's hard to have those conversations too...we have not been offered any support that would kind of push us...into the ways of making those decisions and giving us...the education we might need to make some of those decisions.</p>
<p>Theme 5: Is palliative care about "end-of-life" or about "enhancing quality of life"?</p> <p>Jason Patient: It means my life is coming close to an end.</p> <p>Heather Care Partner: It's enhancing quality of life.</p> <p>Jennifer Care Partner: I think of it [PC] as sort of a whole person, whole family view of the situation and... um, you know, not doing the, "I'm the neurologist. I'm the pulmonary guy."</p>

Conclusion

Patients and families perceive gaps in the delivery of the PC and are open to PC approaches to meet these needs. Providing additional education on the differences between hospice and palliative care is recommended.

Background

- Parkinson's disease (PD) is a complex neurodegenerative disorder impacting everyday function and quality of life.
- Rehabilitation plays a crucial role in improving symptoms, function, and quality of life and reducing disability (1-3).
- However, rehabilitative care is under-recognized and under-utilized in PD and often only utilized in later disease stages, despite research and guidelines demonstrating its positive effects.
- Currently, there is a lack of consensus regarding fundamental topics related to rehabilitative services in PD.
- While there are individual discipline-specific guidelines (e.g., OT, PT, and SLP) and papers on organizing multidisciplinary care, there are no integrated international guidelines outlining key principles of multidisciplinary rehabilitative care in PD. This lack of guidance limits the appropriate inclusion of rehabilitative services in PD and the provision of optimal care for people living with PD.

Objective

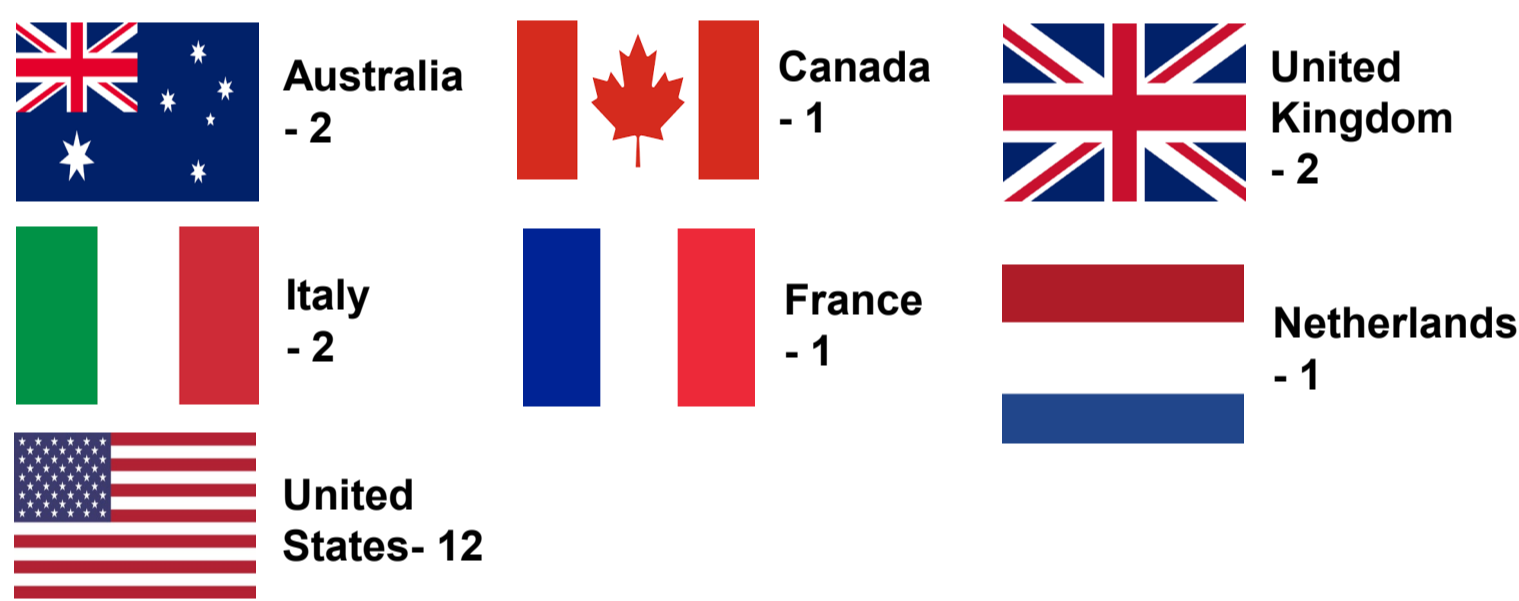
- To develop a consensus statement regarding the incorporation of multidisciplinary rehabilitation in PD care.



Methods

- The Parkinson's Foundation convened a Task Force of 21 international experts in PD representing clinical care and research in PD and rehabilitation and those with lived experience.
- Disciplines represented included:
 - Occupational therapy (OT)
 - Physical therapy (PT)
 - Speech language pathology (SLP)
 - Psychology/neuropsychology
 - Nursing
 - Movement disorders neurology
 - Physiatry
 - Rehabilitation science
 - People living with PD and care partners

Countries represented:



- The Task Force and steering committee met virtually during 2021-2022 to 1) discuss topics such as rehabilitative services, existing therapy guidelines and relevant rehabilitation literature in PD, and identify gaps and needs and 2) develop consensus-based recommendations for rehabilitation care.
- We used the PICOTS framework (i.e., Population, Interventions, Comparisons, Outcomes, Timing, and Settings) to define the scope and parameters of the consensus statement document.
- A modified Delphi process was used to develop the consensus statement using an iterative process, incorporating evidence reviewed and collective expert opinion.
 - Eight virtual workshops were held by the Task Force.
 - Information from the workshops and email communications were reviewed by the steering committee.
 - Task Force members voted on statements electronically, and consensus was based on at least 80% approval.
 - Dissenting opinions were discussed during virtual workshops and resolved with majority agreement.
 - Consensus statement document was then reviewed by external experts in the field.

Results

- The expert-based consensus statement outlines key tenets of rehabilitative care including:
 - its multidisciplinary approach for key tenets, team structure, care planning, timing and settings, and education / training (Excerpts highlighted in Tables 1-3 and Figure 1)
 - discipline-specific guidance for occupational therapy, physical therapy, speech language pathology/therapy, and psychology/neuropsychology across all stages of PD.

TABLE 1. Key principles of rehabilitative care for PD

- Rehabilitative services play an integral role in the comprehensive, integrated model of PD care and should be multidisciplinary and available along the continuum of PD from diagnosis to end of life.
- Rehabilitative care in PD should be considered in the context of other PD treatments as it can be adjunctive to medication and surgical therapies in PD, or for some, at different time points, may be the primary therapeutic intervention.
- Rehabilitation goals should be person-centered and developed in collaboration with the person living with PD and care partners, as appropriate. The process of setting rehabilitation goals is dynamic, requiring assessment and re-evaluation along the continuum of PD. Rehabilitation goals are directed at optimizing physical, psychological, social, and behavioral functioning for persons at all stages of PD.
- Rehabilitative care is grounded in underlying neurobiological mechanisms and includes scientifically driven and personalized interventions.

Results

FIGURE 1. Rehabilitation care team

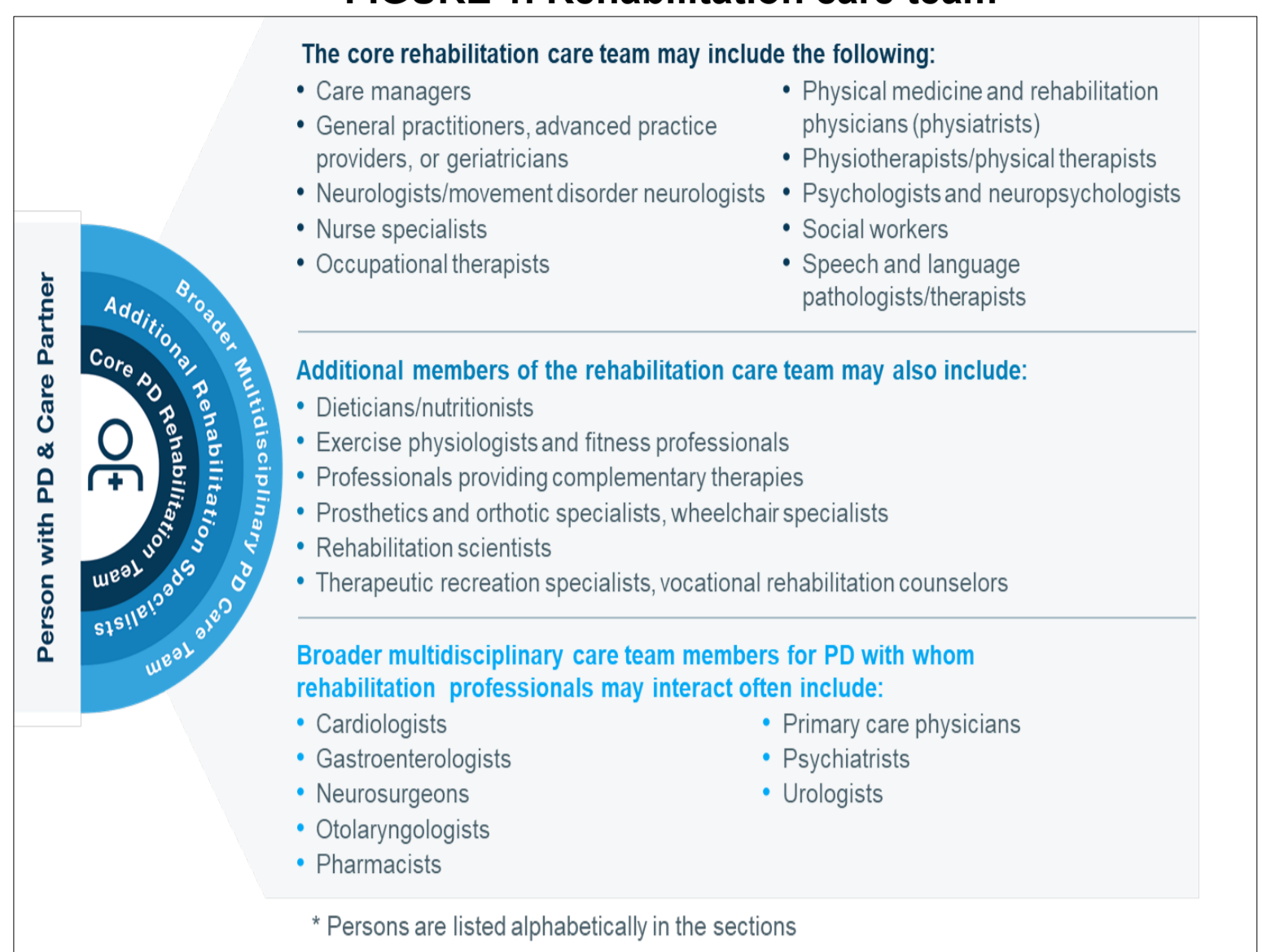


TABLE 2. Care planning for PD rehabilitation

- Rehabilitation team members should provide a tailored, meaningful, person-centered approach when developing treatment plans for persons with PD. Care plans need to account for the goals, needs, preferences, values, and learning style of the person with PD. They should also account for the ability of the person with PD to readily access needed services, such as geographic location of medical offices, insurance coverage, language and culture, and other factors that could limit care utilization.
- Rehabilitation providers should involve the care partner of a person with PD, where appropriate, for management, education, and training, as well as take into account the psychosocial and physical needs of the care partner and the person with PD. It is essential that providers understand the person with PD's and care partner's health literacy, comprehension, and cognition, and their communications need to be tailored appropriately.
- Rehabilitation providers, persons with PD, and care partners, should work together using a shared decision-making approach.
- Rehabilitation providers should teach persons with PD and their care partners self-management strategies at early PD stages and on an ongoing basis throughout the disease course.

TABLE 3. Timing and settings for rehabilitative services

- Rehabilitative services should be implemented across all stages of disease and integrated with other interventions (e.g., medications, surgery), from early stages (which can be as soon as the time of diagnosis) to advanced disease. Services implemented should involve all or any combination of the rehabilitation team disciplines according to the specific changing needs of the person with PD across all stages of the disease.
- Early referral to rehabilitative services should be recommended to individuals as soon as they are diagnosed with PD and should continue with regular modifications throughout disease progression as needed.
- Rehabilitation providers should conduct baseline rehabilitation assessments at first presentation of PD to establish baseline status, with input from the multidisciplinary rehabilitation team, to determine which interventions should be initiated and set rehabilitation goals to optimize function, quality of life, promote a healthy lifestyle, and prevent functional decline.
- Rehabilitation providers should conduct serial and follow up rehabilitation assessments at regular intervals throughout disease progression (e.g., approximately every 6 months or when needed) to determine changes over time, identify new features or concerns about the diagnosis, set new therapy goals, prevent disease-related complications, address patient and care partner needs, and optimize function and quality of life.
- Rehabilitative services can be provided in a variety of settings including: outpatient therapy locations, day rehabilitation programs, inpatient hospital programs, community-based programs, at home, and long-term care facilities, as well as in single-discipline (e.g., physical therapy alone) or multidiscipline (e.g., physical therapy and occupational therapy) settings that take into account of differences in patient needs and resource availability.

Conclusions

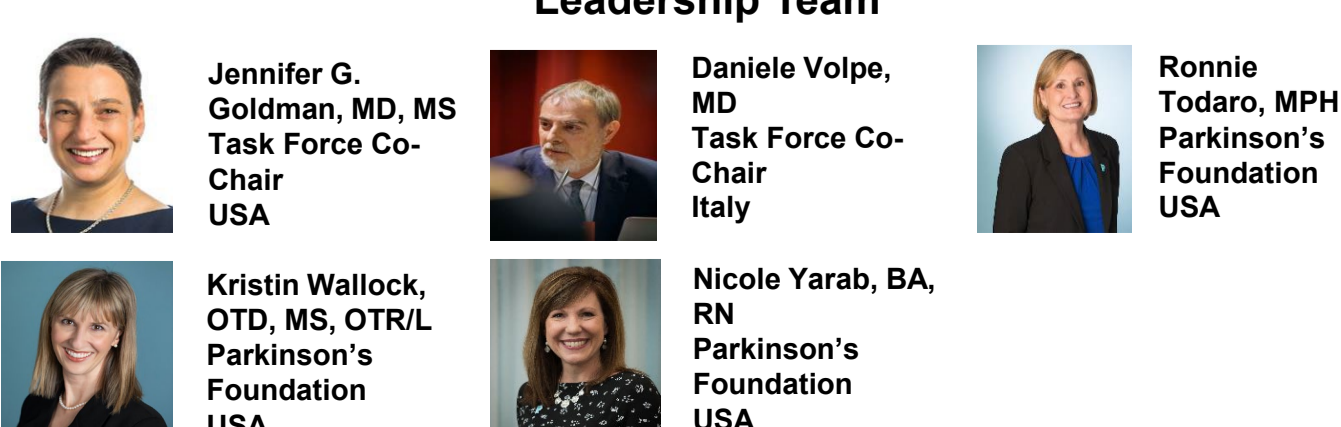
- The consensus-based statements address fundamental components of rehabilitative care for PD and will help establish paradigms for the delivery of high-quality rehabilitative care for PD.
- Given the progressive nature of PD and changes in a person's goals and needs across different stages, rehabilitative care should be offered regularly throughout the disease course with repeat assessments and interventions adapted to changes in a person's condition or needs.
- Rehabilitative interventions should be an essential component in the comprehensive treatment of PD, from diagnosis to advanced disease.
- Greater education and awareness of benefits of rehabilitative services for people with PD and their care partners, and further evidence-based and scientific study are encouraged.

References

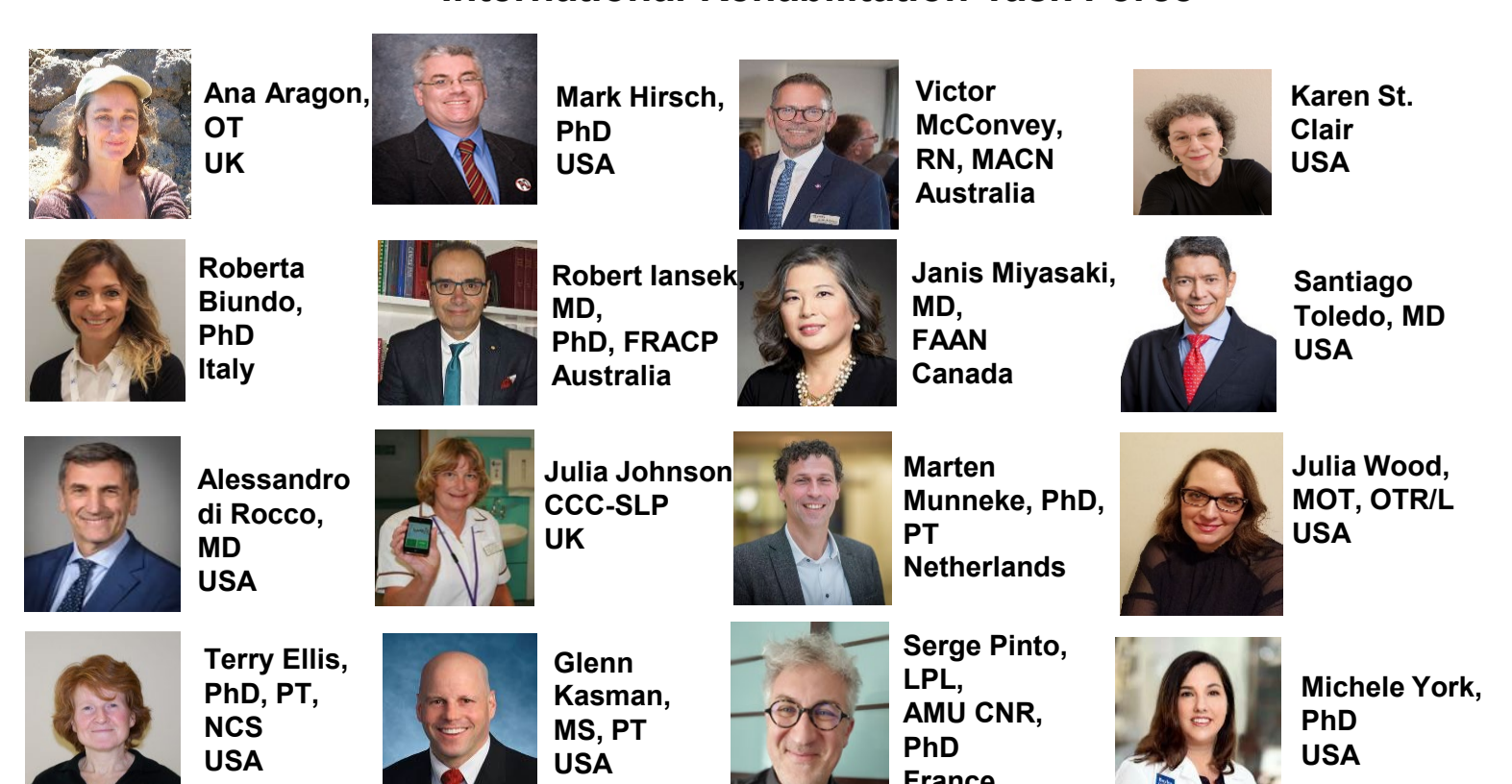
1. Nakache MJ, Keus SH, Oostendorp RA, Overeem S, Mulleners W, Bloem BR, Munneke M (2009) Allied health care in Parkinson's disease: referral, consultation, and professional expertise. *Mov Disord* 24, 282-286.
2. Roberts AC, Rafferty MR, Wu SS, Miao G, Cubillos F, Simuni T (2021) Patterns and predictors of referrals to allied health services for individuals with Parkinson's disease: A Parkinson's foundation (PF) QII study. *Parkinsonism Relat Disord* 83, 115-122.
3. Ferrazzoli D, Ortelli P, Iansek R, Volpe D (2022) Rehabilitation in movement disorders: From basic mechanisms to clinical strategies. *Handb Clin Neurol* 184, 341-355.

Acknowledgements

Leadership Team



International Rehabilitation Task Force





Practice and outcome variation across Parkinson's Foundation Centers of Excellence

Abstract #92

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BACKGROUND

Variation in outcomes between patients with Parkinson's disease (PD) is marked. Some of this variation is likely determined by factors intrinsic to the individual, but treatment practices may also influence outcome.

DESIGN/METHODS

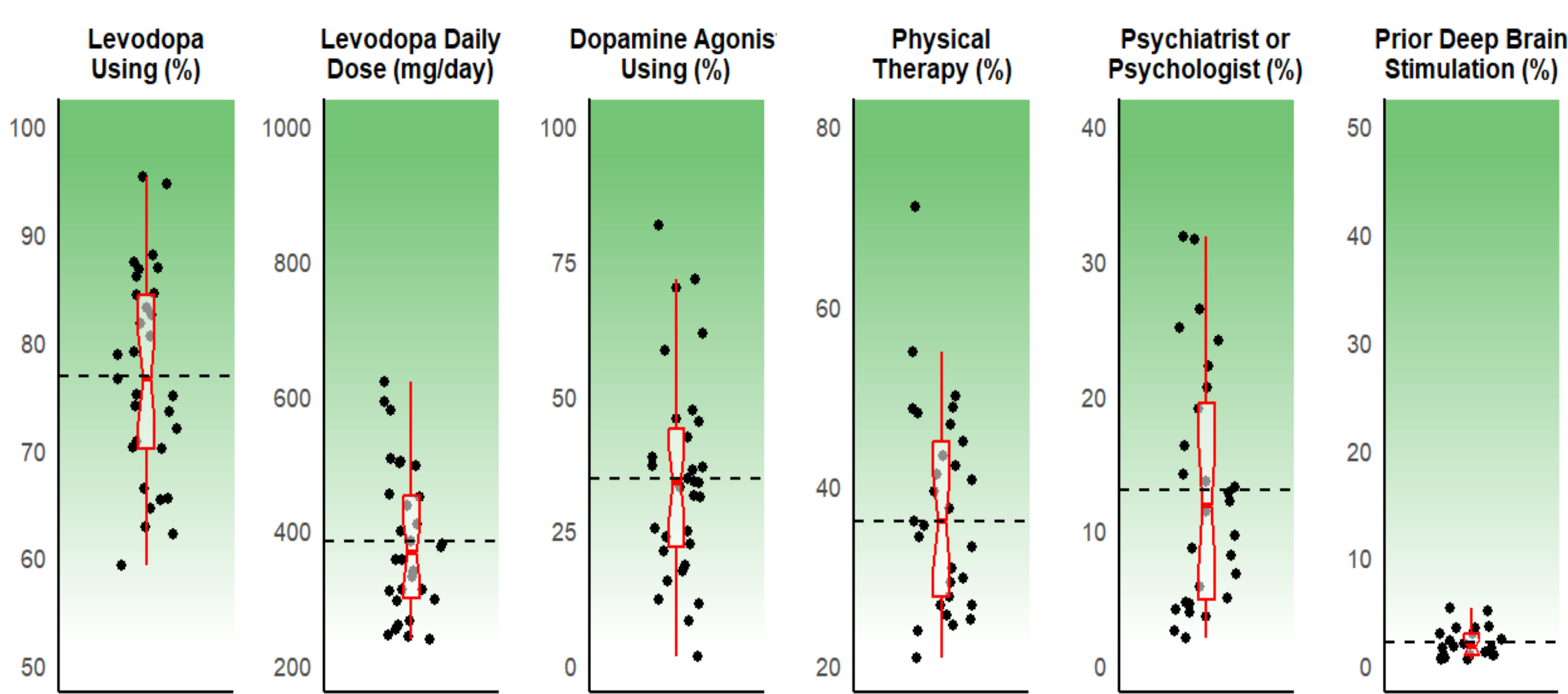
- Parkinson Foundation (PF) Parkinson Outcomes Project data were used, with annual data collection on treatment received and outcomes in context of usual care at PF Centers of Excellence. People with PD seen at the center were enrolled without exclusions.
- Outcome assessments: health related quality of life (Parkinson Disease Questionnaire; PDQ-39), Hoehn and Yahr stage, and fall frequency.
- Adjusting for age, sex, education and number of comorbidities we compared a single center's PD treatment and patient outcomes to the mean value for all centers stratified by disease duration ≤ 5 and >5 years.

RESULTS

- 12,664 PD participants from 31 PF Centers of Excellence were studied, with a mean age 68 (SD 10) and 63% men.
- 6,100 participants had PD duration ≤ 5 years from diagnosis and 6,405 had a PD duration > 5 years at first study visit.

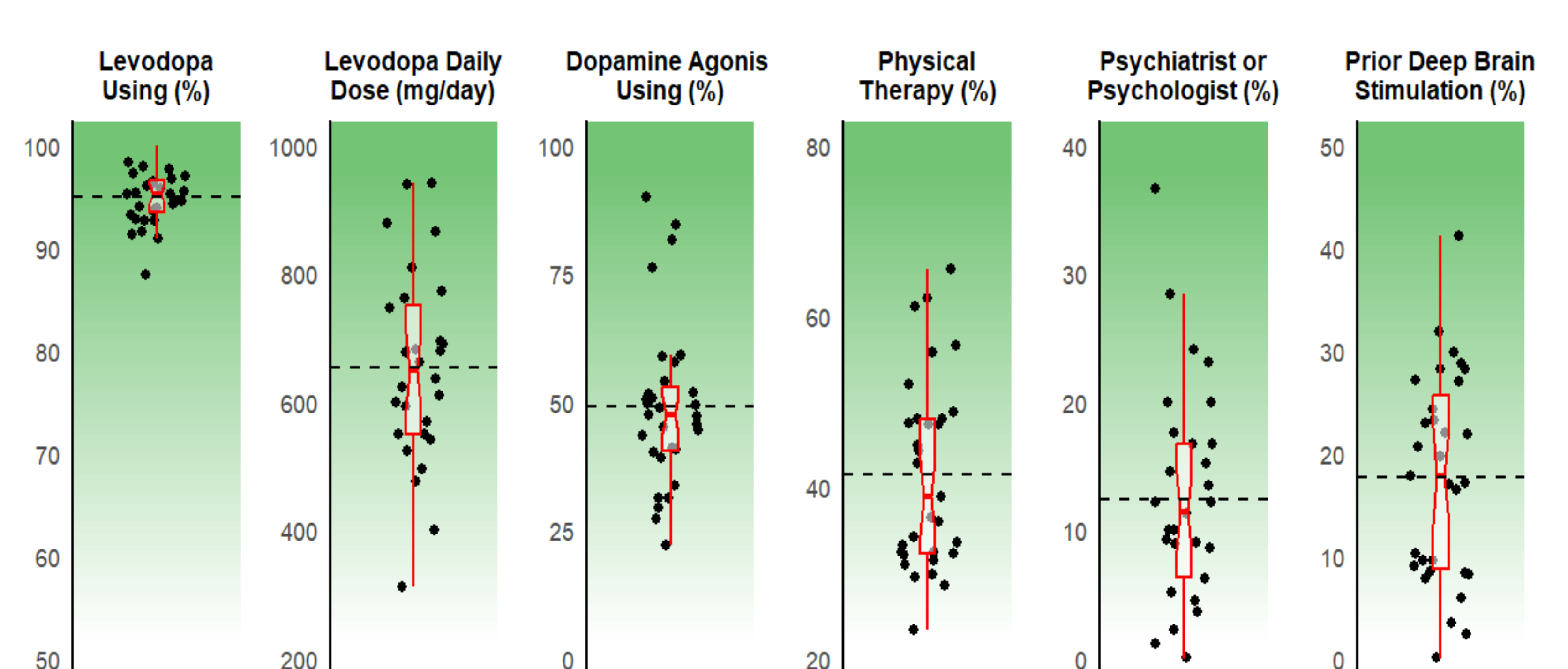
Figure 1: Dose/Frequency of primary treatment practices of interest by center, adjusted for comorbidities, age, sex, level of education

1a: Disease duration from diagnosis ≤ 5



- Levodopa Use: 76% (n=4603) of participants were taking levodopa with 7 centers at a significantly higher (range 82-95%) and 7 centers at a lower proportion (59-74%).
- Mean Levodopa daily dose ranged from 250-600 mg
- Dopamine agonist use varied between 0 and 80% of patients.
- 35% (n=2143) were sent to physical therapy with 9 centers higher (range 39-71%) and 8 centers lower (13-27%) than the center average.

1b: Disease duration from diagnosis >5 years

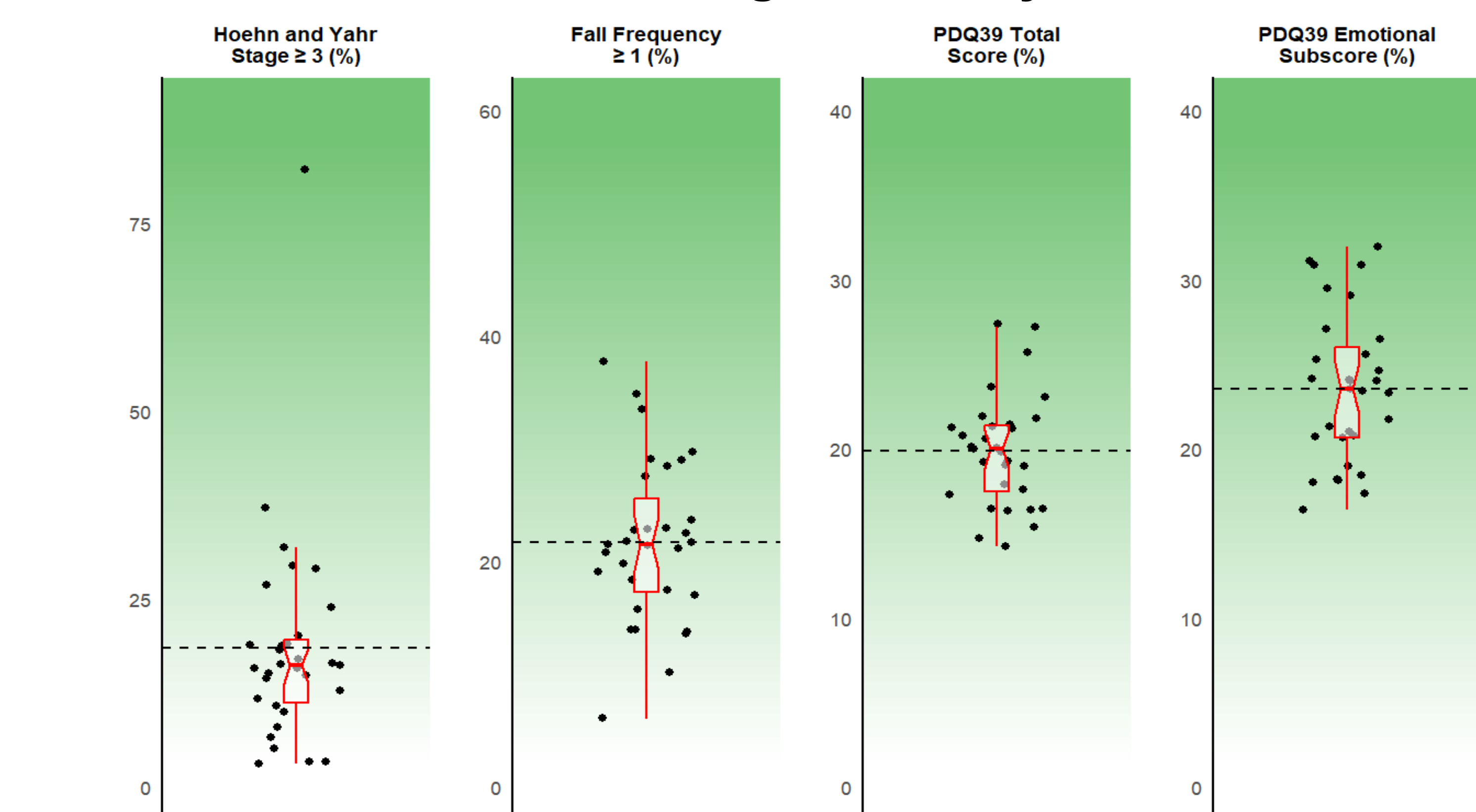


- Mean Levodopa daily dose ranged from 300mg/day to 900mg/day.
- 40% (n=2603) were sent to physical therapy with 8 centers higher (range 48-66%) and 10 centers lower (23-34%) than the mean.
- 20% (n=1251) had received DBS with 12 centers higher (range 22-41%) and 8 centers lower (2-10%) than the center average.

Legend: Q1 -1.5*IQR, Q1, Median, Q3, Q3 +1.5*IQR, mean

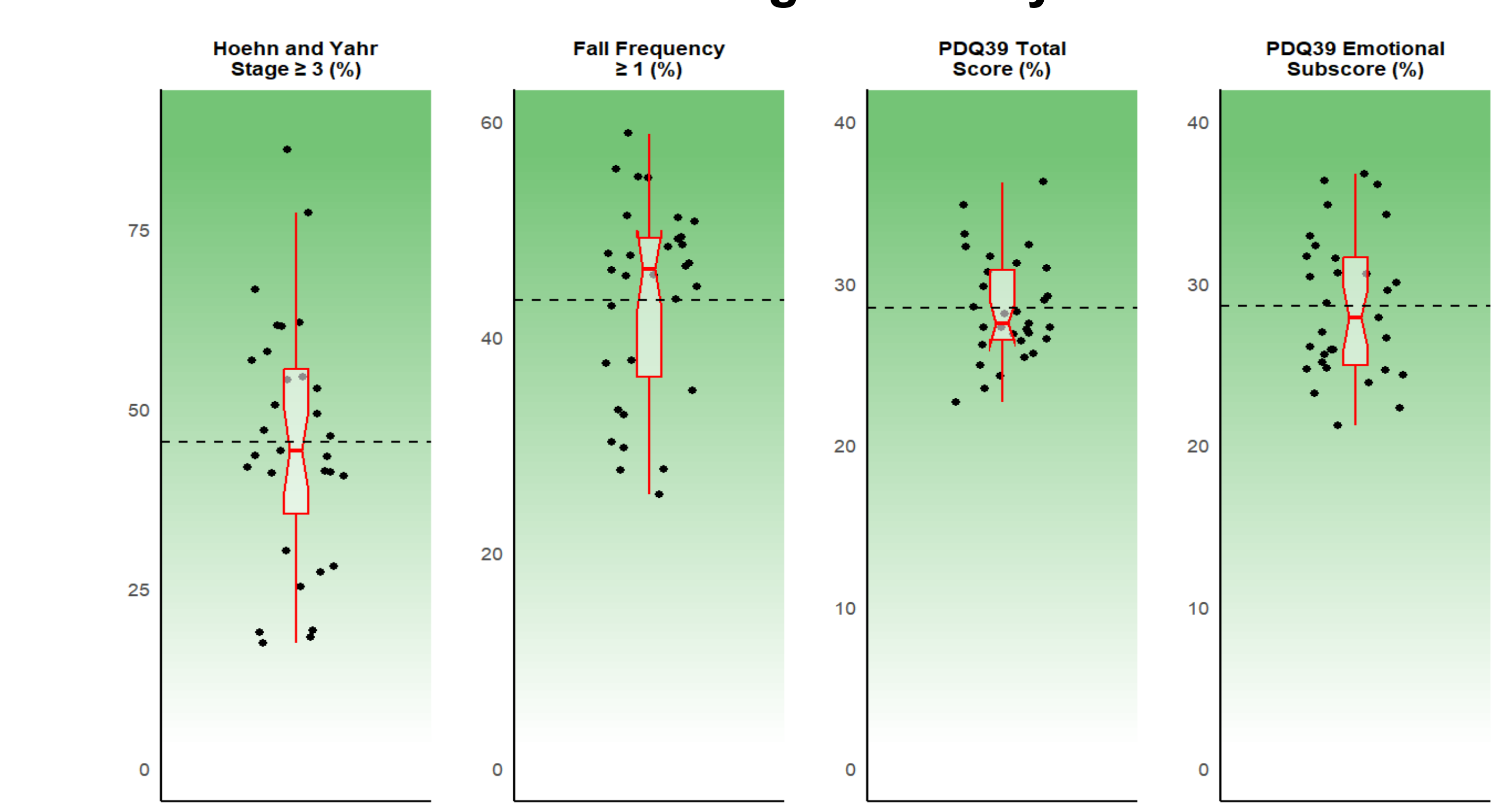
Figure 2: Distribution of outcomes of interest by center, adjusted for comorbidities, age, sex, level of education

2a: Disease duration from diagnosis ≤ 5 years



- Mean PDQ-39 scores were 20 (sd 14) with 8 centers higher (range 21-27) and 6 centers lower (14-18).
- 22% (n=1331) participants had falls with 8 centers higher (range 28-38%) and 6 centers lower (6-16%) than the center average.

2b: Disease duration from diagnosis >5 years



- Mean PDQ-39 scores were 29 (sd 16) with 7 centers higher (range 30-36) and 7 centers lower (23-27).
- 46% (n=2789) participants had falls with 7 centers higher (range 47-59%) and 8 centers lower (25-38%) than the center average.

CONCLUSIONS

There is substantial variation in both PD treatment practices and patient outcomes across centers of excellence. Our future analyses will examine the relationships between treatment patterns and outcomes to help guide high quality clinical care.

ACKNOWLEDGEMENTS

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Parkinson's Team Training Is Beneficial For New and Established PD Centers

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Abstract #1934

OBJECTIVE

To determine if the Parkinson's Foundation (PF) Team Training (TT) empowers Parkinson's disease (PD) interprofessional healthcare teams to make changes in their care plans and treatment coordination that lead to better coordinated care for patients.

BACKGROUND

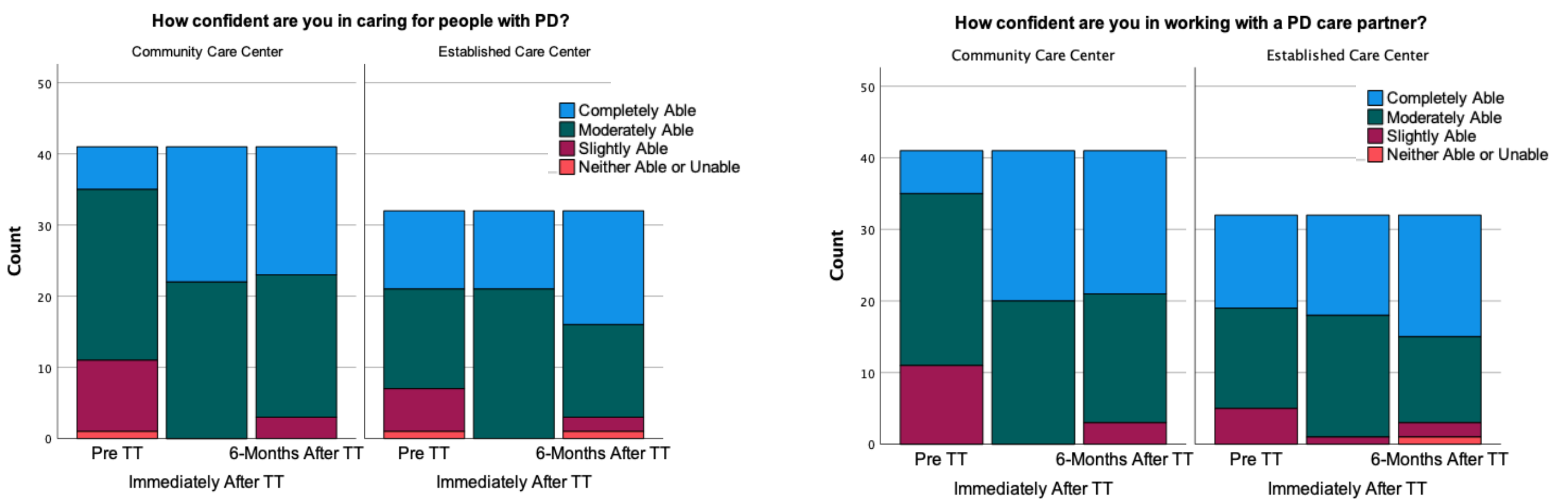
Since 2003, PF has offered the TT program to healthcare professionals in the community, both individual healthcare professionals and those who were working in, or establishing, PD programs using interprofessional care teams. It had not been formally studied as to whether PF TT could also be beneficial to an established PD care team.

METHODS

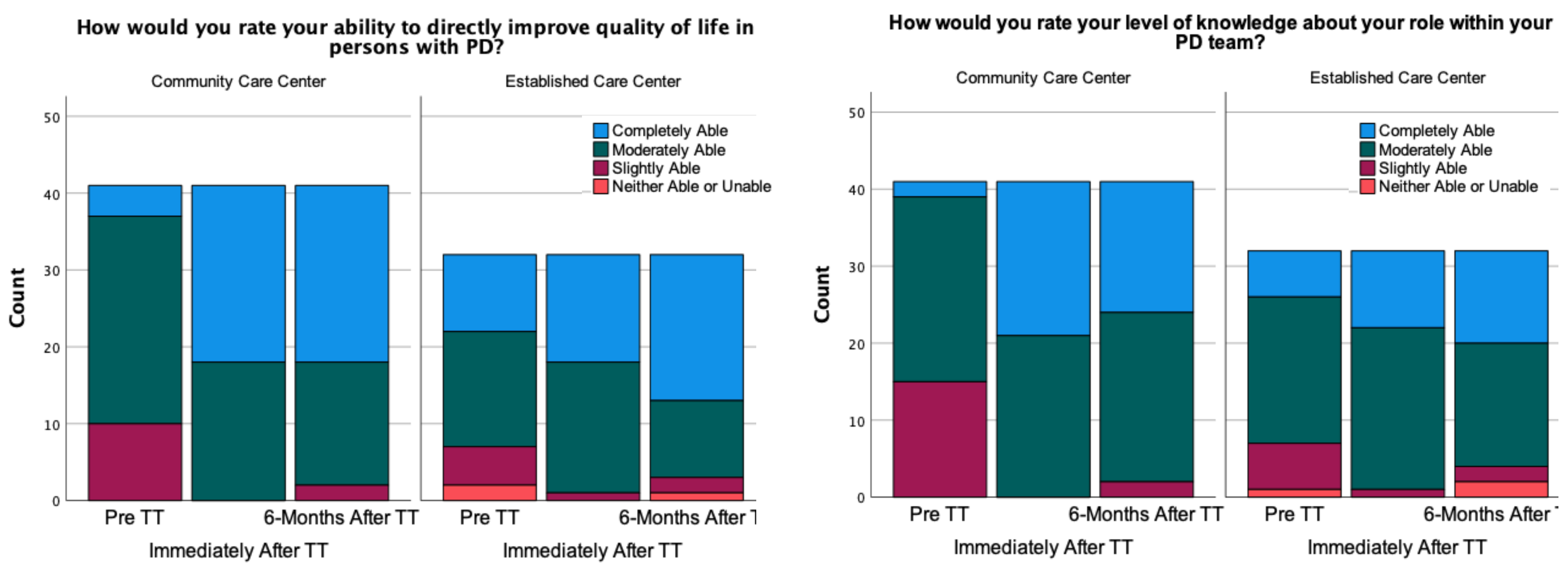
In October 2022, two large PD PF Centers of Excellence, including 39 team members participated in the TT in-person program, along with 53 attendees from various community PD care teams ranging from 3 to 8 team members. All team members were encouraged to attend, including physicians, nurse practitioners, physician assistants, nurses, psychologists, psychiatrists, neuropsychologists, dieticians, pharmacists, occupational, physical, speech, and music therapists, social workers, and other team members working with persons with PD. Participants completed surveys before, immediately after, and 6 months after the training to assess learning and benefit of the program.

RESULTS

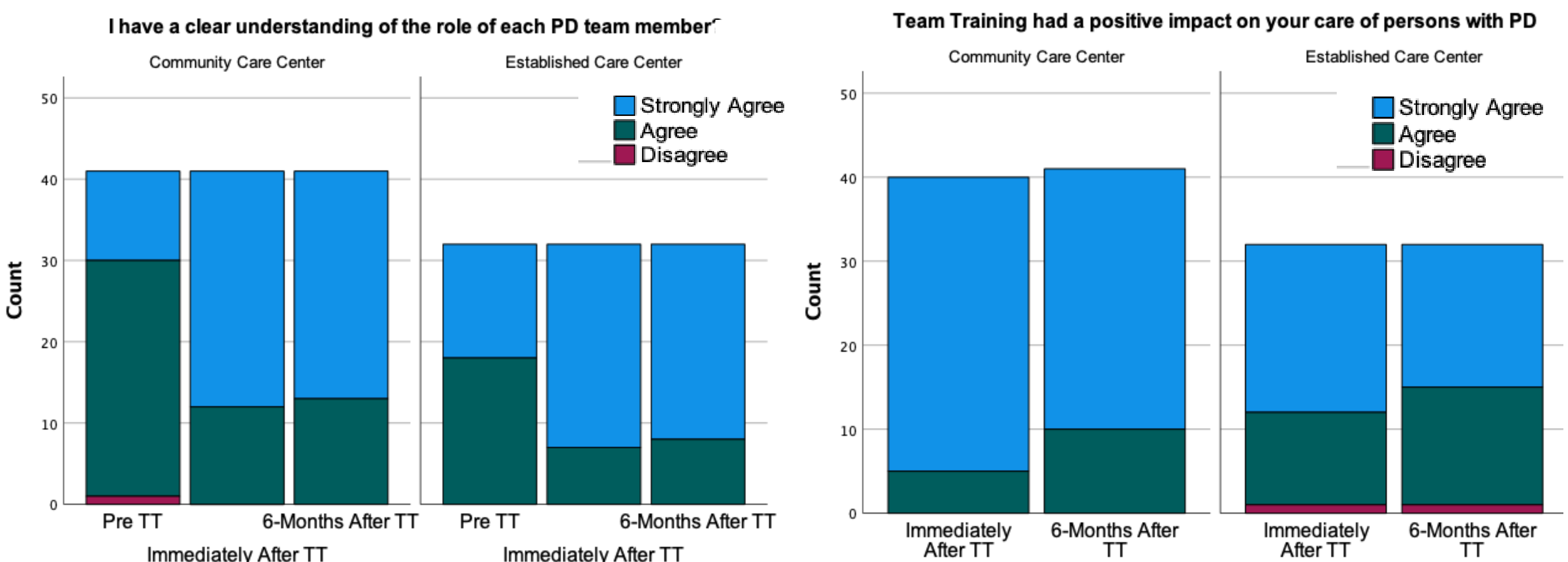
A total of 73 participants completed the pre, immediate and 6-month surveys; 32 from established PD centers and 41 from community care teams. As noted in the graphs below, TT improved the confidence of team members of both community and established PD centers in caring for persons with PD and working with their care partners.



In the community care teams, prior to TT, 10% felt they were completely able to improve QoL in persons with PD and 6 months after TT, this increased to 56%. Similarly, in the established teams, 31% felt they were completely able to improve QoL prior to TT which increased to 59% 6 months after TT. The level of knowledge regarding attendees' own role in the PD care team also increased in both groups.



Prior to TT, 27% of the community team members strongly agreed that they had a clear understanding of the role of each team member which increased to 71% after TT. In the established teams, this increased from 44% before TT and 78% after. Finally, 100% of community teams agreed that TT had a positive impact to their care of persons with PD, compared to 97% of the established team members.



CONCLUSION

Team Training offered by the Parkinson's Foundation was shown to have a positive impact on interprofessional team members of both established and community PD Centers. Attendees were more confident in the care they provide to both those with PD and care partners, more confident to improve quality of life of those with PD, increased their knowledge of the roles of other team members, and better understood their own roles within the PD care teams.