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A New Phase of the Parkinson's Outcomes Project Registry Study

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OBJECTIVE

To provide an update on the Parkinson's Outcomes Project, a longitudinal study measuring outcomes among people with Parkinson's disease (PwP) treated at Parkinson's Foundation Centers of Excellence (COE) across four countries.

BACKGROUND

Data sets collected through the Parkinson's Outcomes Project examine best practices for standard of care across 21 COEs to improve clinical outcomes. The data generated from this study may help identify predictive factors and treatment paradigms that result in better quality of life and longer survival.

METHODS

Data will be prospectively collected annually among PwP and their care partners treated at the participating 21 Parkinson's Foundation Centers of Excellence (COE) across four countries, during a standard-of-care visit without exclusions. Clinical outcomes are measured by the Parkinson's Disease Questionnaire 39 (PDQ-39), along with basic motor and cognitive assessments (Table 1).

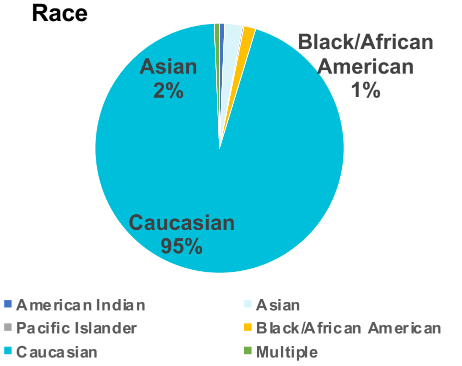
Table 1. Study assessments collected during recurring annual study visits

Study Assessment Categories	Assessments	
Demographic	▪ Age ▪ Sex ▪ Race	▪ Ethnicity ▪ Education Level ▪ Height, Weight
PD Diagnosis/Characteristics	▪ Year of PD diagnosis ▪ Age at onset ▪ Certainty of PD diagnosis ▪ H&Y stage	▪ Dyskinesia ▪ Rest tremors ▪ On/Off status ▪ Duration and frequency of PD care
Living Situation	▪ Marital status ▪ Employment status ▪ Support group status	
Comorbidities	▪ Present/absent/treated/limiting activities	
Clinical Outcomes	▪ Frequency of falls (past 3 months) ▪ Number of hospitalizations (past 12 months) ▪ ER visits (past 12 months) ▪ Reason for hospital admissions	▪ Timed up and Go (TUG) ▪ PDQ-39 ▪ MCSI (Care partner burden) ▪ Cognition (immediate and delayed 5-word recall, verbal fluency)
Medications (type and dosage)	▪ Dopamine-replacement therapies ▪ Other PD medications ▪ Other CNS medications	
Other therapies	▪ Physical therapist ▪ Occupational therapist ▪ Speech language pathologist for communication and/or swallowing	▪ Dietitian ▪ Social worker ▪ Psychologist/Psychiatrist
Deep Brain Stimulation (DBS)	▪ Date of procedure ▪ Probe targets	
Exercise	▪ Frequency ▪ Intensity	

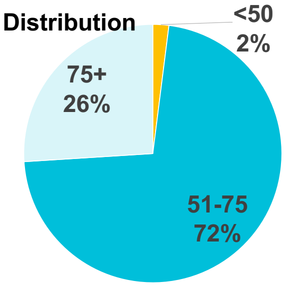
RESULTS

Of the 13,324 individuals in the cohort, 5,468 have remained active in the study, and 1,778 are deceased. The average age of participants entering the study is 65, with an age of onset of 57 and disease duration of 7 years. 95% of the cohort are Caucasian. Among active participants, 72% are aged 51-75, while <2% are younger than 50. The majority of participants (76%) are Hoehn and Yahr (H&Y) stage 2 or 3.

Race



Age Distribution



To further characterize PwP, the study will begin a new phase focusing on participants from underrepresented categories including: young-onset PD (<50 years old), early and late-stage PD (H&Y 1, 4 and 5), minority (non-Caucasian) races and disease duration >10 years. The study will also aim to provide genetic testing to all participants to enhance our understanding of the determinants of PD phenotype and outcomes.

Recruitment Eligibility Criteria

Participants will be recruited if they meet any of the following criteria:

✓Young-onset PD (age at onset <50)
✓Early and late-stage PD (H&Y stage 1, 4, and 5)
✓Minority races (non-Caucasian)
✓Hispanic ethnicity
✓Disease duration >10 years

New Study Features

- Open-access to de-identified data for qualified researchers (pursuant to steering committee approval)
- Genetic testing and counseling to all North American participants through the PD GENEration test panel

CONCLUSION

Longitudinal follow-up across the disease spectrum offers a valuable resource for multiple stakeholders across the PD community. The cohort characteristics highlight the challenges faced when recruiting and/or retaining racial and ethnic minorities, as well as the extremes of age and disease stage. The new data collected among underrepresented groups of PwP, along with their genetic status will address crucial gaps in PD research by enriching our understanding of the disease. Future strategies of this study will be to link genotype data with clinical phenotype and develop a diverse cohort that is representative of the overall PD community, across disease progression.

ACKNOWLEDGEMENTS

The Parkinson's Foundation thanks the participants in the Parkinson's Outcomes Project for their many years of contributing valuable data. This gift serves as a resource for years to come, making possible the opportunity to reframe the study to include underserved populations and to link genetic findings with both short- and long-term outcomes. The study also thanks Zachary Meyer for his contributions to the study.