

PROPARK

Title	Profiling Parkinson's disease (ProPark)
Consortium	<p>Management</p> <p>Clinical lead – Clinical phenotyping Dr. D.H. Hepp, Leiden University Medical Center Previously Prof. Dr. J.J. van Hilten, Leiden University Medical Center Dept. Of Neurology (K5-Q) Albinusdreef 2, 2333 ZA, Leiden T: 071-5262197 E: d.h.hepp@lumc.nl</p> <p>Scientific lead – Molecular profiling Prof. dr. W.D.J. van de Berg, Amsterdam UMC, location VUmc Dept. of Anatomy and Neurosciences De Boelelaan 1117, 1081 HV, Amsterdam T: 06-25694907 E: wdj.vandeberg@vumc.nl</p> <p>Bioinformatic lead – Data architecture and bioinformatics Prof. dr. M.J.T. Reinders, Delft University of Technology Faculty Electrical Engineering, Mathematics and Computer Science Van Mourik Broekmanweg 6, 2628 XE, Delft T: 015-2786424 E: m.j.t.reinders@tudelft.nl</p>
Study	<p>Multicenter study</p> <p>Site 1: Leiden University Medical Center - Dr. D.H. Hepp Site 2: Amsterdam UMC, location VUmc - Prof. dr. H.W. Berendse Site 3: Amsterdam UMC, location AMC - Prof. dr. R.M.A. de Bie Site 4: Erasmus Medical Center - Dr. A.J.W. Boon Site 5: Meander Medical Center, Amersfoort - Dr. M.M. Ponsen</p>
Partners	<p>1: AbbVie Pharmaceuticals 2: Centre of Human Drug Research 3: F. Hoffmann-La Roche Ltd 4: Hersenstichting 5: H. Lundbeck A/S 6: Parkinson Vereniging 7: PHARMO Institute NV 8: Stichting Alkemade</p>
Study Description	<p>The ProPark cohort consists of People with PD (disease duration 0 to 15 years, follow-up 3 years) and healthy subjects (2 year follow-up) who have been characterized comprehensively on clinical, medication use, biospecimen (i.e., genetics, blood biomarker, skin biomarker, stool microbiome) and wearable-sensor-derived free-living kinematic data. The data has been integrated for advanced 'big data' analytic strategies aiming to personalize the current and future treatment strategies in PD.</p>

Study Objectives	To evaluate the role of existing and novel quantitative biomarkers in understanding the heterogeneity in the Parkinson's phenotype (i.e. rate of progression, cognitive and neuropsychiatric impairment and motor dysfunction) and predicting treatment response as well as the occurrence of adverse drug reactions.
Outcome measures ProPark infrastructure	<p>1: Clinical data (physical examination, cognitive tests and neuropsychiatric inventories assessed at baseline and during annual follow-up examinations (T1yrs, T2yrs and T3yrs; table 1).</p> <p>2: Clinical data from home questionnaires including the occurrence and severity of adverse drug reactions (Send at T0, T0.5, T1, T1.5, T2, T2.5 and T3; Fig 1).</p> <p>3: Yearly collected blood samples.</p> <p>4: Yearly collected stool samples.</p> <p>5: Skin biopsies for a subsample of 295 PD patients and 53 controls collected at T0 and T2.</p> <p>6: Wearable sensors data collected yearly for 1 week (at T0, T1, T2, T3).</p> <p>7: MRI, 7 tesla, for a subsample of 107 PD patients collected at T0 and 35 controls. https://github.com/chrisvriend/propark_bids/</p> <p>8: Cortical Spinal Fluid (CSF) for a subsample of 50 PD patients and 9 controls collected at T0 and T2.</p>
Study population & expected no of participants	<p>722 eligible males and females with a diagnosis of Parkinson's Disease confirmed by a neurologist:</p> <ul style="list-style-type: none"> • 41% with a disease duration since diagnosis of ≤ 2 years • 59% with a disease duration since diagnosis of 3-15 years. <p>142 healthy, age and gender-matched controls.</p>
Study design	Longitudinal observational cohort study

Inclusion Criteria

Patients

In order to be eligible to participate in this study, a patient must meet ALL of the following criteria:

- Recently diagnosed with PD (time since Parkinson diagnosis ≤ 2 years) or not recently diagnosed with PD (time since Parkinson diagnosis > 2 & ≤ 15 years) (Time since Parkinson diagnosis (in years) made by a neurologist according to the Movement Disorder Society clinical diagnostic criteria for Parkinson's disease; (Postuma et al., 2015);
- 18 years or older;
- Able to read and understand Dutch;
- Providing IRB-approved Informed Consent;
- Willing, competent and able to comply with all aspects of the protocol, including follow-up schedule and biospecimen collections.

Controls

- 18 years or older
- Healthy (Self-report)
- Similar distribution with respect to gender and age as the patient groups will be attempted
- Providing IRB-approved Informed Consent;
- Willing, competent and able to comply with all aspects of the protocol, including follow-up schedule and biospecimen collections

Exclusion Criteria

A potential participant who meets ANY of the following criteria will be excluded from participation in this study:

Patients

- Patients who received brain surgery for Parkinson's disease, patients who currently use levodopa continuous intestinal gel or patients who are currently receiving apo-morphine treatment.
- Presence of co-morbidities that would hamper interpretation of parkinsonian disability, in the opinion of the Investigator.
- MoCa score of ≤ 16 (indicates dementia) (Biundo et al., 2016)
- Unwillingness to be informed of unexpected medical findings
- Note: patients with a disease duration of ≤ 2 yrs, are excluded if:
 - they are current, recent or past participant in The Personalized Parkinson Project ("de Parkinson op maat studie") from Radboudumc.
- Patients with a disease duration of > 2 & ≤ 15 yrs, are only excluded if they are currently a participant in The Personalized Parkinson Project ("de Parkinson op maat studie") from Radboudumc.

Controls

- A history of neurological disorders that affect the brain or central nervous system
- Abnormal findings at general neurological examination
- Unwillingness to be informed of unexpected medical findings

Participant duration

- Screenings: 1-2 hours x 4 screenings
- Observational period: 2 -3 years

ProPark: Profiling Parkinson's disease



WHY PROPARK?

Understanding heterogeneity in Parkinson's disease (PD). Patients differ widely in disease progression, symptoms, treatment response and adverse drug reactions. Current research and care insufficiently capture these individual differences.

THE PROPARK COHORT

A multi-center longitudinal cohort

👤 850+ participants

👨‍🦳 ~ 700+ people with PD

👤 100+ healthy controls

🕒 3-year, annual, follow-up

THE NETHERLANDS

2021 - 2027

Amsterdam UMC

Leiden UMC

Erasmus MC

Meander MC



RESEARCH LINES

From data to impact

📈 Disease progression and subtyping

💊 Treatment response & adverse drug reactions

🧠 Cognitive & neuropsychiatric outcomes

🔬 Biomarker development

🤖 Data-driven and AI-supported data-analyses

STUDY DESIGN & DATA COLLECTION

● Baseline — ● 1 year — ● 2 years — ● 3 years

At each visit (PD participants):

🏃 Motor assessments

🧠 Cognitive assessments

📱 Wearables

🩸 Blood samples

🗑️ Stool samples

✅ Questionnaires

Controls: baseline and 2-year visit, identical data collection.

Optional assessments:

📱 Smartphone-based data

🌀 MRI

🩺 Skin biopsy

🧴 CSF (liquor)

IMPACT & COLLABORATIONS

Towards personalized medicine

🎯 Improved understanding of Parkinson's heterogeneity

🤝 Platform for academic, clinical and public-private partnerships

📁 Data and samples available upon request

www.proparkinson.nl