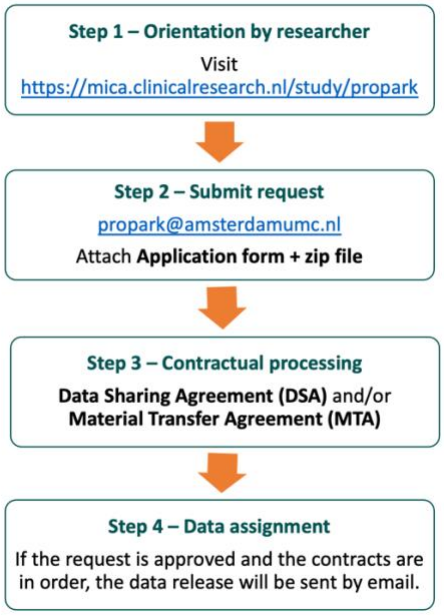
Data and Sample Request Procedure

Procedural overview



Step 1 – Orientation by researcher

- Visit https://mica.clinicalresearch.nl/study/propark.
- View all available ProPark variables (see also: attachment 1). A search function is available, for example using the term "UPDRS".
- Select desired variables and add them to a 'shopping cart'.
- Export the shopping cart as two .csv files (packaged in a zip file).

Step 2 – Submit Request

- Request form is obtained via propark@amsterdamumc.nl or ProPark website. Make sure selection criteria are clear.
- Applicant fills in all required information and sends **form + zip file** to propark@amsterdamumc.nl.
- Requests are reviewed on the first Tuesday of every month.

Step 3 – Contractual processing

- A Data Sharing Agreement (DSA) and/or Material Transfer Agreement (MTA) is prepared and send to the applicant for signature'. This is not required for researchers within the ProPark consortium, provided that samples remain within consortium-affiliated centers.
- The applicant sends completed form to propark@amsterdamumc.nl, after which the biobank manager contacts the legal departments of each ProPark participating center for signing.
- Further processing will take place after the contracts have been signed.
- Please take note of the following:

To support the sustainability of the ProPark infrastructure, a cost-recovery fee applies to the release of **biomaterials and clinical data**. Fees **depend on the type and volume of the request** and cover handling, data processing, and logistics. Academic ProPark partners fall under internal cost-sharing agreements. External academic and commercial applicants are subject to standard fees. Reduced fees for academic collaborations may be granted upon request**. Final cost estimates are provided after internal review and must be accepted before release by signing the MTA / DSA.**

- Publication agreements are mentioned in the DSA / MTA.
- All applicants for ProPark samples and clinical data are asked to provide annual updates regarding the status of their research project and publication. Reminders for this are sent by ProPark.

Step 4 – Ethical testing

- Ethical testing is only required for biomaterial requests, of which the research aims are outside the score of the original ProPark objectives.
- The ProPark biobank manager will send the necessary forms to the applicant (each participating center has its own form).
- Applicant completes the forms and sends it to propark@amsterdamumc.nl.
- The ProPark biobank manager sends the completed forms to the ethical committees and informs the application on the decision of the ethical committee.

Step 5 – Data assignment

- Data release will take place after the contracts have been signed.
- **Data Enrichment in ProPark:** To enhance the scientific value and sustainability of the ProPark cohort, results generated through data sharing will, where possible and in consultation with the applicants, be fed back and integrated into the central ProPark database. This feedback may include analyzed or derived data, novel biomarkers, scoring results, or enriched variables. This process contributes to the continuous enrichment of the dataset and facilitates secondary analyses by other researchers within the consortium, while ensuring data quality, transparency, and adherence to the FAIR principles (Findable, Accessible, Interoperable, Reusable).

Attachment 1

Table 8.3. Data collection overview per timepoint for both patients and healthy controls

Data collection overview		T0 PD	T0 HC	T0.5 PD	T1 PD	T1.5 PD	T2 PD	T2 HC	T2.5 PD	T3 PD
Clinical data										
General data										
Demographics (self report)[1]	🏠	x	x	-	x	-	x	x	-	x
General healthy information (self report)[2]	🏠	x	x	-	x	-	x	x	-	x
PD specific information (self report)[3]	🏠	x	-	-	-	-	-	-	-	-
ADRs & Phenotypic characterization data										
Motor Assessments assessment[4]	⊕	x	x	-	x	-	x	x	-	x
Neuropsychological assessment[5]	📞 ⊕	x	x	-	x	-	x	x	-	x
Neuropsychiatric assessment[6]	📞	x	x	-	x	-	x	x	-	x
Height, leg length & weight	⊕	x	x	-	x	-	x	x	-	x
Orthostatic hypotension	⊕	x	x	-	x	-	x	x	-	x
Neuropsychiatric questionnaires (self-report)[7]	🏠	x	x	x	x	x	x	x	x	x
Other (self report)[8]	🏠	x	x	x	x	x	x	x	x	x
Medication	📞🏠	x	x		x		x	x		x
Biomaterials*										
Stool Sample 5 gr	🏠	x	x	-	x	-	x	x	-	x
EDTA Plasma (DNA)	⊕	x	x	-	-	-	-	-	-	-
PAX Gene (RNA)	⊕	x	x	-	-	-	x	x	-	-
PBMCs	⊕	x	x	-	-	-	x	x	-	-
Plasma	⊕	x	x	-	x	-	x	x	-	x
Serum	⊕	x	x	-	x	-	x	x	-	x
Skin biopsies (α-syn)[9]	⊕	x	x	-	-	-	x	x	-	-
Cerebrospinal fluid[10]	⊕	x	x	-	-	-	x		-	-
MRI[11]	⊕	x	x#	-	-	-	-	-	-	-
Wearable and smartphone data										
Axivity sensors										
Continuous (passive) movement data (Wrist)	🏠	x	x	-	x	-	x	x	-	x
Continuous (passive) movement data (Back)	🏠	x	x	-	x	-	x	x	-	x
Active motor tests	🏠	x	x	X	x	x	x	x	X	x
Smartphone sensors										
Smartphone user interaction	🏠	x	x	-	x	-	x	x	-	x
Active voice test	🏠	x	x	-	x	-	x	x	-	x
Probability of conversations in the subject's proximity	🏠	x	x	-	x	-	x	x	-	x
Relative location	🏠	x	x	-	x	-	x	x	-	x
Questionnaires[12]	🏠	x	x	-	x	-	x	x	-	x

1Demographics: Age at inclusion; Gender; Education; Handedness; Living situation; Work status; Side of wrist sensor.
2General health information: Smoking; Alcohol-use; Marihuana use; Caffeine use; Pesticides/herbicides exposure; Hormone treatments; Family history Parkinson and/or dementia; Walking aide during assessment; Current/passed diseases; Surgery with hospitalization; Head trauma.
3PD specific information: Year first motor symptom PD; Date of diagnosis by neurologist; Side onset first moto symptoms.
4Motor Assessment: UPDRS-III; Hoehn & Yahr stage; timed up-and-go tests; UPDRS-IV ; Rapid Turning Test;; Modified Schwab & England activities of daily living. Motor assessments will be videotaped unless a participant declines.
5Neuropsychological Assessment: UPDRS-I ; Montreal Cognitive Assessment, **Visuospatal functioning:** Pentagon drawing; **6Neuropsychiatric assessment:** SAPS-PD (hallucinations) .
7Neuropsychiatric questionnaire (self-report): Beck Depression Inventory-II; Quip- RS (impulsive compulsive disorder); Parkinson Anxiety Scale; AES-12PD (apathy).
8Other (self-report): UPDRS-II; SCOPA- autonomic; SCOPA- sleep; RBD questionnaire; WO-Q9 (Wearingoff Questionnaire); PDQ-8; New Freezing of Gait Questionnaire; food frequency questionnaire; fall history past 6 months & year; Gait Efficacy Scale.
9 N=400 in patients; N=100 in controls. Alpha-synuclein not available.
10 N=100 in patients; N=50 in controls
11 N=100 in patients