Categories of Datasets: Minimal, Core and Extended

Please note: The items below are meant to serve as a **guide**, and although "hierarchical" there can be overlap (e.g., you may have some missing data for the "Core" dataset, but have other data available for the "Extended" dataset). We would generally also **not** exclude patients/families just because some items are missing (even from the "Minimal" dataset). However, the completeness of the submitted data will potentially influence the prioritization for sample analysis and/or remuneration (if and when available) to participating centres.

1. Minimal dataset

- Part 1, Items 1-5, 7, 10 or 11, 12-14
- Part 2, Items 1-3, 5, 6
- Part 3, Items 1, 3

2. Core dataset

As for Minimal dataset, plus:
- Part 1, Items 6, 8, 9
- Part 2, Items 3, 4, 7, 8
- Part 3, Items 2, 4 (UPDRS or MDS-UPDRS), 6-9

3. Extended dataset

As for Core dataset, plus:
- Part 2, Item 9
- Part 3, Items 4 (Questionnaires/Rating Scales other than UPDRS or MDS-UPDRS), 5
- Part 4

Part 1 - Demographics & Basic Clinical Details

1. Site/Principal Investigator:

2. Patient ID:

3. Date of birth:

4. Sex: ◯Male ◯Female

5. Ethnicity (check all that apply): Dropdown list for:
American Indian / Alaska Native
Arab
Asian; further dropdown for: Chinese; Indian; Filipino; Japanese; Korean; Malay; Central Asian; Other (please state):
Black or African American
European / Caucasian / White
Hispanic / Latino
Jewish (Ashkenazi)
Jewish (non-Ashkenazi)
Native Hawaiian / Other Pacific Islander
Other (please state):
Unknown

6. Consanguinity (*"Are your parents related by blood, for example, could they be cousins?"*)**:**
◯No ◯Yes; please describe: ◯Possibly; please describe:

7. Country where patient has lived most of his/her life: (dropdown list - use MDS/World Bank listing of countries, categorized by income)

8. Education completed:
◯Primary ◯Secondary ◯Tertiary

9. Longest lifetime occupation: (dropdown list)

10. Year of PD motor symptom onset (*"In what year did you first notice difficulties with your movements?"*)**:**
11. Year of PD diagnosis (*"In what year were you first told by your doctor that you have Parkinson's?"*)**:**

12. Criteria used to diagnose PD (can select more than 1)**:**
◯2 out of 3 cardinal motor features (bradykinesia, rigidity and resting tremor), and not more likely to be an alternative diagnosis (e.g., Parkinson-plus syndrome, drug-induced parkinsonism, vascular parkinsonism, etc.)
◯Queen Square Brain Bank Criteria
◯MDS clinical diagnostic criteria for "Clinically Established PD"
◯MDS clinical diagnostic criteria for "Clinically Probable PD"

13. Month and year of last contact:

14. Current status:
◯Under active follow-up
◯Not under active follow-up, but recontactable
◯Deceased; Year of death: ___ Cause of death: ___
◯Unknown or uncontactable

Part 2 - Genotyping & Family History

1. Year of sample collection:

2. Genotyping done?
◯No
◯Yes, and found to have mutation(s) that are at least likely pathogenic in:
◯*PRKN* ◯*DJ-1* ◯*SNCA* ◯*VPS35*
◯*PINK1* ◯*LRRK2* ◯*GBA* ◯Other (please specify):

◯Yes, and found not to have any likely pathogenic mutation related to PD

If answering Yes to Q2:

3. Genotyping platform used (check all that apply)**:**

◯Single/Candidate-gene (Sanger) sequencing
◯Multiplex ligation-dependent probe amplification (MLPA)
◯NGS-based custom PD-gene panel
◯NeuroChip
◯Whole-exome sequencing
◯Whole-genome sequencing

4. Please give detailed description of positive findings (including details at cDNA and protein level, and zygosity, e.g., "*LRRK2*, c.6055G>A, p.G2019S, heterozygous, or "*PRKN*, c.(7+1_8-1)_(171+1_172-1)del, homozygous):
[Provide dropdown list as per MDSGene platform, first with gene, then cDNA and protein level changes, and zygosity]
Or upload report, without patient-identifying details

5. Family member(s) with diagnosed PD (*"Have any members of your immediate or extended family been diagnosed with Parkinson's by a doctor?"*)**:**

◯No ◯Yes; number of relatives diagnosed with PD: ___; please list:

Relationship to index case	Year of birth	Year of PD diagnosis	Genetic diagnosis achieved	Sample availability
1.			◯Not done ◯Negative ◯Yes (Same as index case) ◯Yes (Different from index)	◯Not available ◯No, but contactable ◯Yes

6. Other family member(s) with symptoms suggestive of PD (*"Are there any other family members with symptoms or signs suggestive of Parkinson's"*)**:**

◯No ◯Yes; number of relatives with symptoms but not diagnosed with PD: ___; please list:

Relationship to index case	Year of birth	Year of symptom onset	Genetic diagnosis achieved	Sample availability
1.			◯Not done ◯Negative ◯Yes (Same as index case) ◯Yes (Different from index)	◯Not available ◯No, but contactable ◯Yes

7. Family members with other neurological disorders (*"Have any members of your immediate or extended family been diagnosed with neurological disorders other than Parkinson's, such as a Parkinson-plus syndrome, dementia, motor neuron disease, cerebellar ataxia, dystonia, spastic paraplegia, epilepsy, or intellectual disability?"*)**:**

◯No ◯Yes; number of relatives diagnosed with neurological disorders other than PD: ___; please list:

Relationship to index case	Year of birth	Neurological disorder	Year of diagnosis	Genetic diagnosis achieved	Sample availability
1.				◯Not done ◯Negative ◯Yes; Please specify the mutated gene: ___	◯Not available ◯No, but contactable ◯Yes

8. Healthy immediate family members (without neurological condition):

◯No ◯Yes; number of healthy relatives in the immediate family (parents, siblings) ≥18 years of age: ___; please list:

Relationship to index case	Year of birth	Sample availability
1.		◯Not available

		◯No, but contactable ◯Yes

9. Ethnicity and country of birth of grandparents:
Father's father: (dropdown lists as for Part 1 Q5 above, and Part 1 Q7 above)
Father's mother: (dropdown lists as for Part 1 Q5 above, and Part 1 Q7 above)
Mother's father: (dropdown lists as for Part 1 Q5 above, and Part 1 Q7 above)
Mother's mother: (dropdown lists as for Part 1 Q5 above, and Part 1 Q7 above)

Part 3 - Clinical Features of PD & Investigations

1. Motor features
Year of assessment: ___

Resting tremor	◯No ◯Yes* ◯Unknown	Postural instability / Falls	◯No ◯Yes* ◯Unknown
Postural tremor	◯No ◯Yes* ◯Unknown	Dystonia	◯No ◯Yes ◯Unknown
Action tremor	◯No ◯Yes* ◯Unknown	Clear favourable response to dopaminergic medication	◯No ◯Yes ◯Unknown
Slow movements	◯No ◯Yes* ◯Unknown	Motor fluctuations (ON/OFF periods related to timing of dopaminergic medications)#	◯No ◯Yes ◯Unknown
Rigidity/stiffness	◯No ◯Yes* ◯Unknown	Levodopa-induced dyskinesias#	◯No ◯Yes ◯Unknown
Gait difficulty	◯No ◯Yes* ◯Unknown	Sleep benefit	◯No ◯Yes ◯Unknown
Gait freezing	◯No ◯Yes* ◯Unknown	Upper motor neuron signs (hyperreflexia, plus extensor plantar response or sustained clonus)	◯No ◯Yes ◯Unknown

*If answering Yes, there should be a dropdown list for:
◯Before, or at the time of, PD diagnosis ◯During the disease course

#If answering Yes, there should be a dropdown for:
Date first observed (by history or examination):

2. First motor symptom:

◯Tremor	◯Stiffness / frozen shoulder	◯Gait disorder	◯Other (please specify)
◯Micrographia	◯Impaired manual dexterity	◯General slowing up	◯Unknown

3. Non-motor features
Year of assessment: ___

RBD	◯No ◯Yes ◯Unknown	Impulse control disorders	◯No ◯Yes ◯Unknown
Insomnia	◯No ◯Yes ◯Unknown	Constipation	◯No ◯Yes ◯Unknown

Excessive daytime sleepiness	◯No ◯Yes ◯Unknown	Urinary dysfunction	◯No ◯Yes ◯Unknown
Depression symptoms	◯No ◯Yes ◯Unknown	Orthostatic hypotension	◯No ◯Yes ◯Unknown
Anxiety	◯No ◯Yes ◯Unknown	Pain	◯No ◯Yes ◯Unknown
Mild cognitive impairment	◯No ◯Yes ◯Unknown	Hyposmia	◯No ◯Yes ◯Unknown
Dementia	◯No ◯Yes ◯Unknown	Underweight	◯No ◯Yes ◯Unknown
Visual hallucinations	◯No ◯Yes ◯Unknown	Other (please specify):	

If answering Yes to any of the above items, there should be a dropdown list for:
◯Before, or at the time of, PD diagnosis ◯During the disease course

4. PD rating scales
Please tick any that are available:
(Please give the patient's latest assessments)

◯Hoehn & Yahr; Stage: 1/2/3/4/5; Year of assessment: ___
◯UPDRS; Part III score: ___ ◯ON-medication ◯OFF-medication ◯Not specified); Year of assessment: ___; Total score: ___ ◯ON-medication ◯OFF-medication ◯Not specified); Year of assessment: ___
◯MDS-UPDRS; Part III score: ___ ◯ON-medication ◯OFF-medication ◯Not specified); Year of assessment: ___; Total score: ___ ◯ON-medication ◯OFF-medication ◯Not specified); Year of assessment: ___

◯CISI-PD; scores for Motor signs: ___; Disability: ___; Motor complications (dyskinesia and fluctuations): ___; Cognitive status: ___; Total score: ___; Year of assessment: ___
◯PDQ-39 Total score: ___; Year of assessment: ___
◯NMSS Total score: ___; Year of assessment: ___
◯NMSQ Total score: ___; Year of assessment: ___
◯MOCA Total score: ___; Year of assessment: ___
◯MMSE Total score: ___; Year of assessment: ___
◯SCOPA-AUT Total score: ___; Year of assessment: ___

5. Investigations

Modality	Year of most recent study	Result
◯Brain CT		◯Normal ◯Abnormal; Please give details: ◯Unknown
◯Brain MRI		◯Normal ◯Abnormal; Please give details: ◯Unknown
◯DAT scan/PET		◯Normal ◯Abnormal; Please give details: ◯Unknown
◯Transcranial sonography		◯Normal ◯Abnormal; Please give details: ◯Unknown
◯Smell testing (e.g., UPSIT, Sniffin Sticks - please specify)		◯Normal ◯Abnormal; Please give details: ◯Unknown
◯Polysomnography for RBD		◯Normal ◯Abnormal; Please give details: ◯Unknown

◯Myocardial MIBG scintigraphy		◯Normal ◯Abnormal; Please give details: ◯Unknown
◯Other (please specify)		◯Normal ◯Abnormal; Please give details: ◯Unknown

Treatment of PD

6. Year of assessment (if possible, please use the same assessment year as when the UPDRS/MDS-UPDRS was administered)**:** ___

7. PD medications:

Levodopa	◯No ◯Yes ◯Unknown	MAO-B inhibitor (selegiline, rasagiline)	◯No ◯Yes ◯Unknown
COMT inhibitor (entacapone or opicapone)	◯No ◯Yes ◯Unknown	Anticholinergic (e.g., benzhexol, trihexyphenidyl)	◯No ◯Yes ◯Unknown
Dopamine agonist (e.g., pramipexole, ropinirole, piribedil, rotigotine)	◯No ◯Yes ◯Unknown	Amantadine	◯No ◯Yes ◯Unknown

8. Levodopa-equivalent daily dosage (LEDD): ___ mg/d
(Please use the LEDD calculator provided)

9. Device-aided therapies for PD:

Functional neurosurgery	◯No ◯Yes; Year of surgery: ___ ◯Unknown
Apomorphine infusion	◯No ◯Yes; Year commenced: ___ ◯Unknown
Levodopa-carbidopa intestinal gel	◯No ◯Yes; Year commenced: ___ ◯Unknown

Part 4 - Environmental/Acquired Factors Prior to PD Motor Symptom Onset

1. Diabetes mellitus	◯No ◯Yes ◯Unknown
2. Gout	◯No ◯Yes ◯Unknown
3. *Helicobacter pylori* infection	◯No ◯Yes ◯Unknown
4. Irritable bowel syndrome	◯No ◯Yes ◯Unknown
5. Inflammatory bowel disease	◯No ◯Yes ◯Unknown
6. Appendicectomy	◯No ◯Yes ◯Unknown
7. Vagotomy	◯No ◯Yes ◯Unknown
8. Melanoma	◯No ◯Yes ◯Unknown
9. Chronic hepatitis B infection	◯No ◯Yes ◯Unknown

10. Chronic hepatitis C infection	◯No ◯Yes ◯Unknown
11. Chronic renal failure	◯No ◯Yes ◯Unknown

Behavioural/Environmental history using:

12. Mini Environmental Risk Questionnaire (MERQ-PD-B) (covering pesticides, other chemicals, caffeine, smoking, head injury)

13. PD Risk Factor Questionnaire (RFQ-U) for “Physical activity and Sleep”