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  ☐ Deceased; Year of death: ___ Cause of death: ___  
   - ☐ Not under active follow-up, but recontactable  ☐ 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:

<table>
<thead>
<tr>
<th>Relationship to index case</th>
<th>Year of birth</th>
<th>Year of PD diagnosis</th>
<th>Genetic diagnosis achieved</th>
<th>Sample availability</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
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</tr>
</tbody>
</table>

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:

<table>
<thead>
<tr>
<th>Relationship to index case</th>
<th>Year of birth</th>
<th>Year of symptom onset</th>
<th>Genetic diagnosis achieved</th>
<th>Sample availability</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
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</tbody>
</table>

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:

<table>
<thead>
<tr>
<th>Relationship to index case</th>
<th>Year of birth</th>
<th>Neurological disorder</th>
<th>Year of diagnosis</th>
<th>Genetic diagnosis achieved</th>
<th>Sample availability</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
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</tbody>
</table>

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:

<table>
<thead>
<tr>
<th>Relationship to index case</th>
<th>Year of birth</th>
<th>Sample availability</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
<td>Not available</td>
</tr>
</tbody>
</table>
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: ___

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

*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:

<table>
<thead>
<tr>
<th>Feature</th>
<th>No</th>
<th>Yes*</th>
<th>Unknown</th>
<th>No</th>
<th>Yes*</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tremor</td>
<td></td>
<td></td>
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<tr>
<td>Stiffness / frozen shoulder</td>
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<tr>
<td>Gait disorder</td>
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<tr>
<td>Other (please specify)</td>
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<tr>
<td>Micrographia</td>
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<tr>
<td>Impaired manual dexterity</td>
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<tr>
<td>General slowing up</td>
<td></td>
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<tr>
<td>Unknown</td>
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</tbody>
</table>

3. Non-motor features
Year of assessment: ___

<table>
<thead>
<tr>
<th>Feature</th>
<th>No</th>
<th>Yes*</th>
<th>Unknown</th>
<th>No</th>
<th>Yes*</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>RBD</td>
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<tr>
<td>Impulse control disorders</td>
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<tr>
<td>Insomnia</td>
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<tr>
<td>Constipation</td>
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<td></td>
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<tr>
<td>Unknown</td>
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<td></td>
</tr>
</tbody>
</table>
### 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: ___
- 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

<table>
<thead>
<tr>
<th>Modality</th>
<th>Year of most recent study</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brain CT</td>
<td>Normal</td>
<td>Abnormal; Please give details: Unknown</td>
</tr>
<tr>
<td>Brain MRI</td>
<td>Normal</td>
<td>Abnormal; Please give details: Unknown</td>
</tr>
<tr>
<td>DAT scan/PET</td>
<td>Normal</td>
<td>Abnormal; Please give details: Unknown</td>
</tr>
<tr>
<td>Transcranial sonography</td>
<td>Normal</td>
<td>Abnormal; Please give details: Unknown</td>
</tr>
<tr>
<td>Smell testing (e.g., UPSIT, Sniffin Sticks - please specify)</td>
<td>Normal</td>
<td>Abnormal; Please give details: Unknown</td>
</tr>
<tr>
<td>Polysomnography for RBD</td>
<td>Normal</td>
<td>Abnormal; Please give details: Unknown</td>
</tr>
</tbody>
</table>
Part 4 - Environmental/Acquired Factors
Prior to PD Motor Symptom Onset

<table>
<thead>
<tr>
<th>Condition</th>
<th>No</th>
<th>Yes</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Diabetes mellitus</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Gout</td>
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<tr>
<td>3. <em>Helicobacter pylori</em> infection</td>
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<tr>
<td>4. Irritable bowel syndrome</td>
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<tr>
<td>5. Inflammatory bowel disease</td>
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<td></td>
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<tr>
<td>6. Appendicectomy</td>
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<td></td>
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<tr>
<td>7. Vagotomy</td>
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<tr>
<td>8. Melanoma</td>
<td></td>
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<tr>
<td>9. Chronic hepatitis B infection</td>
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<td></td>
</tr>
</tbody>
</table>
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”