

Minimal Data Set

A Patient Data

- A1. Patient randomly selected according to Sampling Procedure? ☐ yes ☐ no
- A2. Patient recruited as out-patient ☐ yes ☐ no
- A3. Date of birth mm-yyyy
- A4. Gender ☐ female ☐ male
- A5. Date of examination dd-mm-yyyy
- A6. Diagnosis:

Please enter patients diagnosed with iPD only.

The other options are given in case the diagnosis is revised at a later date.

- | | |
|---------------------------|-----------------------|
| iPD | ☐ |
| MSA | ☐ |
| CBD | ☐ |
| DLB | ☐ |
| PSP | ☐ |
| drug-induced parkinsonism | ☐ |

others:

- A7. Time of symptom onset: mm-yyyy

If month not known, enter NK for month.

B Clinical Data

As assessed at time of current examination

B1. Hoehn and Yahr (H&Y) stage

For Patients on drug therapy use ON value

B2. UPDRS II

Use historical information of the previous week, regarding overall performance (ON and OFF combined).

B3. UPDRS III

For Patients on drug therapy use ON value

For items B4 through B19 in case of any doubt or lack of information, answer NO.
For definitions and diagnostic criteria click HELP.

	Yes	No
B4. Motorfluctuations	☐	☐
If YES specify:		
B4.1 wearing-off	☐	☐
B4.2 ON-OFF fluctuations	☐	☐
B5. ON-period dyskinesias	☐	☐
If YES specify:		
disabling	☐	☐
B6. OFF-period dystonia	☐	☐
If YES specify:		
disabling	☐	☐
B7. Freezing of gait	☐	☐
B8. Falls	☐	☐

	Yes	No
B9. Dementia	☐	☐
B10. Psychosis	☐	☐
B11. Depressive disorder	☐	☐
If YES specify:		
B11.1 past	☐	☐
B11.2 current	☐	☐

B12. Orthostatic hypotension	☐	☐
B13. Male erectile dysfunction	☐	☐

Rate YES in case of subjective complaint.
If patient is female answer NO.

B14. Urinary incontinence	☐	☐
B15. Chronic constipation	☐	☐

B16. Sleep disorders	☐	☐
If YES specify:		
B16.1 insomnia	☐	☐

Rate YES in case of subjective complaint of poor sleep irrespective of cause.

B16.2 daytime sleepiness	☐	☐
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Rate YES in case of subjective complaint or caregiver observation of daytime sleepiness/sedation.

	Yes	No
B16.3 REM behaviour disorder	☐	☐

YES only in accordance with the ICSD criteria (at least **Minimal Criteria B** plus C).

B17. PD related pain

☐☐

Rate YES with any score above zero on item 17 of UPDRS II.

B18. Currently on anti-parkinsonian medication

☐☐

B19. Deep brain surgery

☐☐

B20. First degree relative with PD or tremor

☐☐

If YES specify:

parent

☐☐

sibling

☐☐

B21. DNA sample available

☐☐

C Drug History

By means of this form the entire drug history of the patient shall be documented. Please enter previous and current drug exposure. Ensure that you mark the drug that was given as first treatment. For follow-up visits the form will open complete and you will enter changes only.

In case of missing information rate NO

	Yes	No	
C1. Levodopa preparations	☐	☐	
If YES specify:			
	ever exposed	discontinued because of side effects	received as first drug treatment
C1.1 L-Dopa Standard	☐	☐	☐
C1.2 L-Dopa Slow Release	☐	☐	☐
C1.3 L-Dopa Soluble	☐	☐	☐
C1.4 L-Dopa-Ethylester	☐	☐	☐
C1.5 L-Dopa Dual Release	☐	☐	☐
C1.6 Others	☐	☐	☐

→ if YES: specify (use generic name)

	Yes	No	
C2. Dopamine agonists	☐	☐	
If YES specify:			
	ever exposed	discontinued because of side effects	received as first drug treatment
C2.1 Alpha-Dihydroergocryptine	☐	☐	☐
C2.2 Apomorphine	☐	☐	☐
C2.3 Bromocriptine	☐	☐	☐

C2.4 Cabergoline	☐	☐	☐
C2.5 Lisuride	☐	☐	☐
C2.6 Pergolide	☐	☐	☐
C2.7 Piribedil	☐	☐	☐
C2.8 Pramipexole	☐	☐	☐
C2.9 Ropinirole	☐	☐	☐
C2.10 Rotigotine	☐	☐	☐
C2.11 Sumanitrole	☐	☐	☐
C2.12 Others	☐	☐	☐

→ if YES: specify *(use generic name)*

	Yes	No
C3. MAO-B Inhibitors	☐	☐
If YES specify:		
	ever exposed	discontinued because of side effects
		received as first drug treatment
C3.1 Selegiline	☐	☐
C3.2 Rasagiline	☐	☐
C3.3 Others	☐	☐

→ if YES: specify *(use generic name)*

ever exposed discontinued because of side effects received as first drug treatment

☐☐

7



	discontinued	received
ever	because of	as first
exposed	side effects	drug treatment

☐

7

9





ever exposed	discontinued because of side effects	received as first drug treatment
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9

D Current drug treatment

Please determine which medication the patient is currently taking. The possible overlapping with the information given in part C "drug history" is intended and will ease data entry for follow-up visits.

	Yes	No
D1. Current treatment of <u>Parkinsonism</u> ?	☐	☐
If YES specify:		
D1.1 Levodopa preparations	☐	☐
If YES specify:		
D1.1.1 L-Dopa Standard	☐	☐
D1.1.2 L-Dopa Slow Release	☐	☐
D1.1.3 L-Dopa Soluble	☐	☐
D1.1.4 L-Dopa Ethylester	☐	☐
D1.1.5 L-Dopa Dual Release	☐	☐
D1.1.6 Others	☐	☐
If YES specify:		
	Use generic name	
D1.1.7 Date of initiation of Levodopa therapy		
	mm-yyyy	
	If month not known, enter NK for month.	

	Yes	No
D1.2 Dopamine agonists	☐	☐
If YES specify:		
D1.2.1 Alpha-Dihydroergocryptine	☐	☐
D1.2.2 Apomorphine	☐	☐
D1.2.3 Bromocriptine	☐	☐
D1.2.4 Cabergoline	☐	☐
D1.2.5 Lisuride	☐	☐
D1.2.6 Pergolide	☐	☐
D1.2.7 Piribedil	☐	☐
D1.2.8 Pramipexole	☐	☐
D1.2.9 Ropinirole	☐	☐
D1.2.10 Rotigotine	☐	☐
D1.2.11 Sumanirole	☐	☐
D1.2.12 Others	☐	☐

If YES specify:

Use generic name

	Yes	No
D1.3 MAO-B-inhibitors	☐	☐
If YES specify:		
D1.3.1 Selegiline	☐	☐
D1.3.2 Rasagiline	☐	☐
D1.3.3 Others	☐	☐

If YES specify:

Use generic name

	Yes	No
D1.4 COMT-inhibitors	☐	☐
If YES specify:		
D1.4.1 Entacapone	☐	☐
D1.4.2 Tolcapone	☐	☐
D1.4.3 Others	☐	☐
If YES specify:		
<i>Use generic name</i>		

	Yes	No
D1.5 Antiglutamate agents	☐	☐
If YES specify:		
D1.5.1 Amantadine	☐	☐
D1.5.2 Budipine	☐	☐
D1.5.3 Memantine	☐	☐
D1.5.4 Others	☐	☐
If YES specify:		
<i>Use generic name</i>		

	Yes	No
D1.6 Anticholinergics	☐	☐

	Yes	No
D2. Current treatment of <u>Depression</u>	☐	☐

If YES specify:

D2.1 Tricyclic- and tetracyclic antidepressants	☐	☐
D2.2 Monoamine oxidase inhibitors	☐	☐
D2.3 Selective serotonin reuptake inhibitor	☐	☐
D2.4 SNaRIs/NaSSAs/NaRIs *	☐	☐
D2.5 Others	☐	☐

If YES specify:

Use generic name

	Yes	No
D3. Current treatment of <u>Psychosis</u>	☐	☐

If YES specify:

D3.1 Clozapine	☐	☐
D3.2 Olanzapine	☐	☐
D3.3 Quetiapine	☐	☐
D3.4 Risperidone	☐	☐
D3.5 Others	☐	☐

If YES specify:

Use generic name

* Serotonin noradrenergic reuptake inhibitors (SNaRIs),
 Noradrenergic and specific serotonergic antidepressants (NaSSAs),
 Selective noradrenaline reuptake inhibitors (NaRIs)

	Yes	No
D4. Current treatment of <u>Dementia</u>	☐	☐

If YES specify:

D4.1 Donepezil	☐	☐
D4.2 Galantamine	☐	☐
D4.3 Memantine	☐	☐
D4.4 Rivastigmine	☐	☐
D4.5 Tacrine	☐	☐
D4.6 Others	☐	☐

If YES specify:

Use generic name

	Yes	No
D5. Current treatment of <u>Erectile dysfunction</u>	☐	☐

If YES specify:

D5.1 Apomorphine	☐	☐
D5.2 Sildenafil	☐	☐
D5.3 Others	☐	☐

If YES specify:

Use generic name

	Yes	No
D6. Current treatment of <u>Urinary dysfunction</u>	☐	☐

If YES specify:

D6.1 Oxybutinin	☐	☐
D6.2 Tamsulosin	☐	☐
D6.3 Tolterodine	☐	☐

	Yes	No
D6.4 Others	☐	☐

If YES specify:

Use generic name

	Yes	No
D7. Current treatment of <u>Orthostatic dysfunction</u>	☐	☐

If YES specify:

D7.1 Dihydroergotamine	☐	☐
D7.2 Etilefrine	☐	☐
D7.3 Fludrocortisone	☐	☐
D7.4 Midodrine	☐	☐
D7.5 Others	☐	☐

If YES specify:

Use generic name

	Yes	No
D8. Current treatment of <u>Sleep disorders</u>	☐	☐

If YES specify:

D8.1 Benzodiazepine	☐	☐
D8.2 Modafinil	☐	☐
D8.3 Zolpidem/Zolpicone	☐	☐
D8.4 Others	☐	☐

If YES specify:

Use generic name

E Clinical trial history

E1. Interest in participating in clinical trials

Yes

No

☐

☐

E2. Currently participating in trial

☐

☐

If YES specify:

Intervention (study drug or procedure in case of surgical trial)

E3. Participation in past trials

Yes

No

☐

☐

If YES specify:

E3.1.1 Intervention (study drug or procedure in case of surgical trial)

E3.2.1 Termination date

mm-yyyy

If month not known, enter NK for month

E3.1.2 Intervention (study drug or procedure in case of surgical trial)

E3.2.2 Termination date

mm-yyyy

If month not known, enter NK for month

Form completed

dd.mm.yyyy

Signature

Signature of investigator