



# Discovery Study Questionnaire

Parkinson's Disease Group  
Physician Questionnaire  
Visit 1

Version 2, 10/05/2016

Attach Patient ID Sticker:

Patient Initials

Patient D.O.B:

Patient Sex: ☐ <sub>1</sub> ☐ <sub>2</sub>  
Male Female

Interviewer ID: \_\_\_\_\_

Visit Date: \_\_\_\_\_

## T. PAST MEDICAL HISTORY

Have you ever been told by a doctor that you have, or have had, any of the following?

- |  |  |   |
|--|--|---|
| 1. Angina  | <input type="checkbox"/> <sub>1</sub><br>YES | <input type="checkbox"/> <sub>2</sub><br>NO |
| 2. Heart Failure (shortness of breath due to heart problems)           | <input type="checkbox"/> <sub>1</sub><br>YES | <input type="checkbox"/> <sub>2</sub><br>NO |
| 3. Stroke or mini-stroke (TIA – transient ischaemic attack)            | <input type="checkbox"/> <sub>1</sub><br>YES | <input type="checkbox"/> <sub>2</sub><br>NO |
| 4. Heart attack (coronary thrombosis, myocardial infarction)           | <input type="checkbox"/> <sub>1</sub><br>YES | <input type="checkbox"/> <sub>2</sub><br>NO |
| 5. Diabetes  | <input type="checkbox"/> <sub>1</sub><br>YES | <input type="checkbox"/> <sub>2</sub><br>NO |
| 6. High cholesterol level  | <input type="checkbox"/> <sub>1</sub><br>YES | <input type="checkbox"/> <sub>2</sub><br>NO |
| 7. High Blood Pressure   | <input type="checkbox"/> <sub>1</sub><br>YES | <input type="checkbox"/> <sub>2</sub><br>NO |
| 8. Lung Cancer   | <input type="checkbox"/> <sub>1</sub><br>YES | <input type="checkbox"/> <sub>2</sub><br>NO |
| 9. Bowel/Colon Cancer  | <input type="checkbox"/> <sub>1</sub><br>YES | <input type="checkbox"/> <sub>2</sub><br>NO |
| 10. <b>APPLIES TO MEN ONLY</b> (check NO for women)<br>Prostate Cancer | <input type="checkbox"/> <sub>1</sub><br>YES | <input type="checkbox"/> <sub>2</sub><br>NO |
| 11. Breast Cancer  | <input type="checkbox"/> <sub>1</sub><br>YES | <input type="checkbox"/> <sub>2</sub><br>NO |
| 12. Melanoma   | <input type="checkbox"/> <sub>1</sub><br>YES | <input type="checkbox"/> <sub>2</sub><br>NO |

## T. PAST MEDICAL HISTORY (CONT)

13. Asthma ☐<sub>1</sub> ☐<sub>2</sub>  
YES NO
14. Chronic Bronchitis ☐<sub>1</sub> ☐<sub>2</sub>  
YES NO
15. Emphysema ☐<sub>1</sub> ☐<sub>2</sub>  
YES NO
16. Rheumatoid Arthritis ☐<sub>1</sub> ☐<sub>2</sub>  
YES NO
17. Gout ☐<sub>1</sub> ☐<sub>2</sub>  
YES NO
18. **APPLIES TO MEN ONLY** (check NO for women)  
Have you ever had a prostate biopsy? ☐<sub>1</sub> ☐<sub>2</sub>  
YES NO

19. If YES to above, please give details (year, hospital): \_\_\_\_\_

20. Have you ever had a colonic or gastric biopsy? ☐<sub>1</sub> ☐<sub>2</sub>  
YES NO

21. If YES to above, please give details (year, hospital): \_\_\_\_\_

22. Have you had any fractures resulting from falls in the last 3 years? ☐<sub>1</sub> ☐<sub>2</sub>  
YES NO

If yes, provide details and date of the event: \_\_\_\_\_

23. Have you had any acute admissions to a hospital in the past year?

☐<sub>1</sub> ☐<sub>2</sub>  
YES NO

If yes, provide details (date, hospital): \_\_\_\_\_

24. If you have had any other illness, please specify: \_\_\_\_\_

## U. MERQ-PD-B

1. Over your lifetime, have you ever had a job in which you used any type of pesticide, including herbicides, insecticides, fungicides, or fumigants? (0 = No, 1 = Yes, 9 = Uncertain) ☐
2. Over your lifetime, were you ever exposed to pesticides including herbicides, insecticides, fungicides or fumigants used on your home, lawn, garden or on a pet? (0 = No, 1 = Yes, 9 = Uncertain) ☐
3. Over your lifetime, have you ever worked with chemical solvents for more than 6 months? (0 = No, 1 = Yes, 9 = Uncertain) ☐
4. Over your lifetime, have you ever worked with heavy metals for more than 6 months? (0 = No, 1 = Yes, 9 = Uncertain) ☐
5. Over your lifetime, have you ever worked with any other chemicals or fumes for more than 6 months? (0 = No, 1 = Yes, 9 = Uncertain)  
If Yes to above, specify: \_\_\_\_\_ ☐
6. Before you were diagnosed with PD, on average, how many cups of a caffeine containing beverage (e.g., coffee, tea, soda) did you drink each day, during the times you were drinking caffeine-containing beverages?
7. At present, how many cups of a caffeine containing beverage do you drink on a typical day?
8. Before you were diagnosed with PD, did you ever smoke cigarettes regularly, that is at least 1 cigarette per day for at least 6 months? (0 = No, 1 = Yes, 9 = Uncertain) ☐
- 8.1 If yes, for how many years did you smoke cigarettes regularly?
- 8.2 If yes, during the time that you smoked regularly, about how many cigarettes did you smoke per day?
9. Do you smoke cigarettes regularly now? (0 = No, 1 = Yes, 9 = Uncertain) ☐
- 9.1 If yes, how many cigarettes do you smoke per day?



**U. MERQ-PD-B  
(CONT)**

10. Before you were diagnosed with PD, did you live with a smoker? ☐  
(0 = No, 1 = Yes, 9 = Uncertain)
11. Before you were diagnosed with PD, did you ever have a head injury where you lost consciousness or were diagnosed with a concussion by a doctor? ☐  
(0 = No, 1 = Yes, 9 = Uncertain)
- 11.1 If Yes, in what year did the head injury occur?
12. **APPLIES TO WOMEN ONLY:** Before you were diagnosed with PD, ☐  
did you ever have one or both ovaries surgically  
removed? (0 = No, 1 = Yes, 9 = Uncertain, N = for male)
- 12.1 If Yes, in what year did the surgery occur?
13. Before you were diagnosed with PD (or at any time, if you don't have PD) ☐  
were you ever diagnosed with depression?  
(0 = No, 1 = Yes, 9 = Uncertain)
- 13.1 If yes, in what year?
14. Before you were diagnosed with PD (or at any time, if you don't have PD) ☐  
were you ever diagnosed with anxiety?  
(0 = No, 1 = Yes, 9 = Uncertain)
- 14.1 If yes, in what year?
15. Before you were diagnosed with PD, on average, how many units of alcohol   
did you drink in a week (pint of beer=2U; pint of lager=3U; wine 175ml=2U;  
sherry 50ml=1U; spirit 25ml=1U)?
16. At present, how many units of alcohol do you drink in a week?

## V. MODIFIED SCHWAB & ENGLAND ACTIVITIES OF DAILY LIVING

100%	Completely independent. Able to do all chores without slowness, difficulty or impairment. Essentially normal. Unaware of any difficulty.
90%	Completely independent. Able to do all chores with some degree of slowness, difficulty and impairment. Might take twice as long. Beginning to be aware of difficulty.
80%	Completely independent in most chores. Takes twice as long. Conscious of difficulty and slowness.
70%	Not completely independent. More difficulty with some chores. Three to four times as long in some. Must spend a large part of the day with chores.
60%	Some dependency. Can do most chores, but exceedingly slowly and with much effort. Errors; some impossible.
50%	More dependent. Help with half, slower, etc. Difficulty with everything.
40%	Very dependent. Can assist with all chores but few alone.
30%	With effort, now and then does a few chores alone or begins alone. Much help needed.
20%	Nothing alone. Can be a slight help with some chores. Severe invalid.
10%	Totally dependent, helpless. Complete invalid.
0%	Vegetative functions such as swallowing, bladder, and bowel functions are not functioning. Bedridden.

A. The subject's PD symptoms during the past week were:

A. ☐

1 = Non Fluctuator (record scores in "ON" column only)

2 = Fluctuator (record scores in "ON" and "OFF" columns)

Consensus rating

ON  
1a. ☐☐☐

OFF  
1b. ☐☐☐

(Investigator, patient, other sources)

## X. PD FEATURES

1. Date of first symptom onset:	<input type="text"/> <input type="text"/>	MM	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	YYYY	
1.1 If patient cannot remember the month, ask for season (1=Winter, 2=Spring, 3=Summer, 4=Autumn)					<input type="text"/>
2.1 Date of Parkinson's disease diagnosis:	<input type="text"/> <input type="text"/>	DD	<input type="text"/> <input type="text"/>	MM	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
				YYYY	
2.2 1 = Actual (ACT), 2 = Day Estimated (Day), 3 = Mon/Day Est. (MD), 4 = Month Est. (Mon)					<input type="text"/>
3. Were the following symptoms present at the time of diagnosis? (0 = No, 1 = Yes, U = Unknown)					
	Clinician reported		Patient reported		
3.1 Resting Tremor/ Tremor of hands at rest	<input type="text"/> <sub>1</sub>		<input type="text"/> <sub>2</sub>		
3.2 Rigidity/ Stiffness of the body on movement	<input type="text"/> <sub>1</sub>		<input type="text"/> <sub>2</sub>		
3.3 Bradykinesia/ Slowness of movement	<input type="text"/> <sub>1</sub>		<input type="text"/> <sub>2</sub>		
3.4 Postural instability/ Balance problems	<input type="text"/> <sub>1</sub>		<input type="text"/> <sub>2</sub>		
3.5 Other	<input type="text"/> <sub>1</sub>		<input type="text"/> <sub>2</sub>		
specify: Clinician reported: _____					
Patient reported: _____					
4. Side predominantly affected at onset (1 = Left, 2 = Right, 3 = Symmetric)	<input type="text"/> <sub>1</sub>		<input type="text"/> <sub>2</sub>		

## Y. FAMILY HISTORY

1. Are you adopted

☐<sub>1</sub> YES

☐<sub>2</sub> NO

Nº of relatives (N if not known)	Nº with PD with a type of diagnosis					Nº alive	Nº with other neurological conditions
	p.m.	hospital doctor	GP	unclear	age diagn.		Comment
2. Biological Mother	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>11</sub>	<input type="checkbox"/> <sub>5</sub>	<input type="checkbox"/> <sub>6</sub> .....
PD meds (0 – No, 1 – Yes, N – not known)	<input type="checkbox"/> <sub>7</sub>	<input type="checkbox"/> <sub>8</sub>	<input type="checkbox"/> <sub>9</sub>	<input type="checkbox"/> <sub>10</sub>			
3. Biological Father	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>11</sub>	<input type="checkbox"/> <sub>5</sub>	<input type="checkbox"/> <sub>6</sub> .....
PD meds (0 – No, 1 – Yes, N – not known)	<input type="checkbox"/> <sub>7</sub>	<input type="checkbox"/> <sub>8</sub>	<input type="checkbox"/> <sub>9</sub>	<input type="checkbox"/> <sub>10</sub>			
4. Patient's Identical Twin (N=n/k, 0=none, 1=one) <input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>	<input type="checkbox"/> <sub>12</sub>	<input type="checkbox"/> <sub>6</sub>	<input type="checkbox"/> <sub>7</sub> .....
PD meds (0 – No, 1 – Yes, N – not known)	<input type="checkbox"/> <sub>8</sub>	<input type="checkbox"/> <sub>9</sub>	<input type="checkbox"/> <sub>10</sub>	<input type="checkbox"/> <sub>11</sub>			
5. Patient's Non-Identical Twins <input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>	<input type="checkbox"/> <sub>12</sub>	<input type="checkbox"/> <sub>6</sub>	<input type="checkbox"/> <sub>7</sub> .....
PD meds (0 – No, 1 – Yes, N – not known)	<input type="checkbox"/> <sub>8</sub>	<input type="checkbox"/> <sub>9</sub>	<input type="checkbox"/> <sub>10</sub>	<input type="checkbox"/> <sub>11</sub>			
6. Other Full Siblings <input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>	<input type="checkbox"/> <sub>12</sub>	<input type="checkbox"/> <sub>6</sub>	<input type="checkbox"/> <sub>7</sub> .....
PD meds (0 – No, 1 – Yes, N – not known)	<input type="checkbox"/> <sub>8</sub>	<input type="checkbox"/> <sub>9</sub>	<input type="checkbox"/> <sub>10</sub>	<input type="checkbox"/> <sub>11</sub>			
7. Half Siblings <input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>	<input type="checkbox"/> <sub>12</sub>	<input type="checkbox"/> <sub>6</sub>	<input type="checkbox"/> <sub>7</sub> .....
PD meds (0 – No, 1 – Yes, N – not known)	<input type="checkbox"/> <sub>8</sub>	<input type="checkbox"/> <sub>9</sub>	<input type="checkbox"/> <sub>10</sub>	<input type="checkbox"/> <sub>11</sub>			
8. Maternal Grandparents <input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <sub>4</sub>	<input type="checkbox"/> <sub>5</sub>	<input type="checkbox"/> <sub>12</sub>	<input type="checkbox"/> <sub>6</sub>	<input type="checkbox"/> <sub>7</sub> .....
PD meds (0 – No, 1 – Yes, N – not known)	<input type="checkbox"/> <sub>8</sub>	<input type="checkbox"/> <sub>9</sub>	<input type="checkbox"/> <sub>10</sub>	<input type="checkbox"/> <sub>11</sub>			

## Y. FAMILY HISTORY

N° of relatives (N if not known)	N° with PD with a type of diagnosis					N° alive	N° with other neurological conditions
	p.m.	hospital doctor	GP	unclear	age diagnos ed		Comment
9. Paternal Grandparents <input type="text"/> <sub>1</sub>	<input type="text"/> <sub>2</sub>	<input type="text"/> <sub>3</sub>	<input type="text"/> <sub>4</sub>	<input type="text"/> <sub>5</sub>	<input type="text"/> <sub>12</sub>	<input type="text"/> <sub>6</sub>	<input type="text"/> <sub>7</sub> .....
PD meds (0 – No, 1 – Yes, N – not known)	<input type="text"/> <sub>8</sub>	<input type="text"/> <sub>9</sub>	<input type="text"/> <sub>10</sub>	<input type="text"/> <sub>11</sub>			
10. Maternal Aunts and Uncles <input type="text"/> <input type="text"/> <sub>1</sub>	<input type="text"/> <sub>2</sub>	<input type="text"/> <sub>3</sub>	<input type="text"/> <sub>4</sub>	<input type="text"/> <sub>5</sub>	<input type="text"/> <sub>12</sub>	<input type="text"/> <sub>6</sub>	<input type="text"/> <sub>7</sub> .....
PD meds (0 – No, 1 – Yes, N – not known)	<input type="text"/> <sub>8</sub>	<input type="text"/> <sub>9</sub>	<input type="text"/> <sub>10</sub>	<input type="text"/> <sub>11</sub>			
11. Paternal Aunts and Uncles <input type="text"/> <input type="text"/> <sub>1</sub>	<input type="text"/> <sub>2</sub>	<input type="text"/> <sub>3</sub>	<input type="text"/> <sub>4</sub>	<input type="text"/> <sub>5</sub>	<input type="text"/> <sub>12</sub>	<input type="text"/> <sub>6</sub>	<input type="text"/> <sub>7</sub> .....
PD meds (0 – No, 1 – Yes, N – not known)	<input type="text"/> <sub>8</sub>	<input type="text"/> <sub>9</sub>	<input type="text"/> <sub>10</sub>	<input type="text"/> <sub>11</sub>			
12. Children <input type="text"/> <input type="text"/> <sub>1</sub>	<input type="text"/> <sub>2</sub>	<input type="text"/> <sub>3</sub>	<input type="text"/> <sub>4</sub>	<input type="text"/> <sub>5</sub>	<input type="text"/> <sub>12</sub>	<input type="text"/> <sub>6</sub>	<input type="text"/> <sub>7</sub> .....
PD meds (0 – No, 1 – Yes, N – not known)	<input type="text"/> <sub>8</sub>	<input type="text"/> <sub>9</sub>	<input type="text"/> <sub>10</sub>	<input type="text"/> <sub>11</sub>			
13. Other Family Members with PD or a Neurological Disease <input type="text"/> <sub>1</sub>	<input type="text"/> <sub>2</sub>	<input type="text"/> <sub>3</sub>	<input type="text"/> <sub>4</sub>	<input type="text"/> <sub>5</sub>	<input type="text"/> <sub>12</sub>	<input type="text"/> <sub>6</sub>	<input type="text"/> <sub>7</sub> .....
PD meds (0 – No, 1 – Yes, N – not known)	<input type="text"/> <sub>8</sub>	<input type="text"/> <sub>9</sub>	<input type="text"/> <sub>10</sub>	<input type="text"/> <sub>11</sub>			

## Z. PD MEDICATION

Ask for current medication first, then past medication.

PD Related Medications include but are not limited to:

Amantadine	CoEnzyme Q	Levodopa/Carbidopa	Ropinirole	Selegiline
Anticholinergics	Bromocriptine	Cognitive Enhancers (e.g. donepezil)	Pergolide	Rasagiline
Antidepressants	Cabergoline	Levodopa/Benserazide	Pramipexole	

Row #	MEDICATION (List generic name, if possible)	EACH DOSE	UNITS (e.g., mg, cc, ml, puffs)	FREQUENCY (e.g. 1, 2, 3 per day)	ROUTE	START DATE (DD/MM/YYYY)	1 = Actual (ACT) 2 = Day Est. (DAY) 3 = Mon/Day Est (MD) 4 = Month Est. (MON)	STOP DATE (DD/MM/YYYY)	1 = Actual (ACT) 2 = Day Est. (DAY) 3 = Mon/Day Est (MD) 4 = Month Est. (MON)	ONGOING 0 = No 1 = Yes	INDICATION
					1 = IV 2 = IM 3 = PO 4 = SC 5 = PR 6 = Sublingual 7 = Inhaled 8 = Topical 9 = Other						
1.											
2.											
3.											
4.											
5.											
6.											
7.											

Levodopa Equivalent Daily Dose (LEDD) calculation: calculate daily dose of a given medication in milligrams and multiply accordingly: dihydroergocryptin x 5; bromocriptine and apomorphine x 10; rotigotine x 30; ropinirole x 20; lisuride, pergolide, pramipexole and cabergoline x 100; levodopa with decarboxylase inhibitor x 1; controlled release levodopa with decarboxylase inhibitor x0.75; levodopa with decarboxylase and COMT inhibitor x 1.3; selegiline oral x 10; selegiline sublingual x 80; rasagiline x 100; amantadine x 1

## AA. CLINICAL GLOBAL IMPRESSION OF CHANGE

Please select your assessment of the response to antiparkinson therapy for this patient's Parkinson signs and symptoms. You should grade the response to antiparkinson treatment, and NOT whether the patient's PD has worsened over time. Leave blank if patient on no antiparkinson therapy.

- |                        |                          |
|------------------------|--------------------------|
| 1. Very much improved  | <input type="checkbox"/> |
| 2. Much improved       | <input type="checkbox"/> |
| 3. Minimally improved  | <input type="checkbox"/> |
| 4. No change           | <input type="checkbox"/> |
| 5. Minimally worse     | <input type="checkbox"/> |
| 6. Much worse          | <input type="checkbox"/> |
| 7. Very much worse     | <input type="checkbox"/> |
| 8. No medication tried | <input type="checkbox"/> |

## AB. OTHER MEDICATION 1

	Use 0= No use 1= Irregular past use 2= Regular past use 3 =Irregular curr.use 4= Regular curr. use	If currently using, leave year of last use blank		Average Dose (# of tablets per week)
		Year of 1st use	Year of Last use	
1. Over-the-counter Nonsteroidal Anti-Inflammatory (NSAID), paracetamol	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <input type="checkbox"/> <sub>4</sub>
2. Cox-2-Inhibitor	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <input type="checkbox"/> <sub>4</sub>
3. Other Nonsteroidal Anti-Inflamm. (NSAID)	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <input type="checkbox"/> <sub>4</sub>
4. Lipid Lowering Statin Drug	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <input type="checkbox"/> <sub>4</sub>
5. Oral Contraceptives	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <input type="checkbox"/> <sub>4</sub>
6. Hormone Replacement Therapy	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <input type="checkbox"/> <sub>4</sub>
7. L-type Calcium antagonists (felodipine, isradipine, nicardipine, nifedipine, nimodipine, nitrendipine, lacidipine, lercadipine)	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <input type="checkbox"/> <sub>4</sub>
8. L-type Calcium antagonist (amlodipine)	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <input type="checkbox"/> <sub>4</sub>
9. Neuroleptics	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <sub>3</sub>	<input type="checkbox"/> <input type="checkbox"/> <sub>4</sub>



## AC. OTHER MEDICATION 2

	Use 1= Irregular past use 2= Regular past use 3 =Irregular curr. use 4= Regular curr. use	If currently using, leave year of last use blank		Average Dose (# of tablets per week)
		Year of 1st use	Year of Last use	
1.	<div><div></div><div>1</div></div>	<div><div></div><div></div><div></div><div></div><div></div><div>2</div></div>	<div><div></div><div></div><div></div><div></div><div></div><div>3</div></div>	<div><div></div><div></div><div>4</div></div>
2.	<div><div></div><div>1</div></div>	<div><div></div><div></div><div></div><div></div><div></div><div>2</div></div>	<div><div></div><div></div><div></div><div></div><div></div><div>3</div></div>	<div><div></div><div></div><div>4</div></div>
3.	<div><div></div><div>1</div></div>	<div><div></div><div></div><div></div><div></div><div></div><div>2</div></div>	<div><div></div><div></div><div></div><div></div><div></div><div>3</div></div>	<div><div></div><div></div><div>4</div></div>
4.	<div><div></div><div>1</div></div>	<div><div></div><div></div><div></div><div></div><div></div><div>2</div></div>	<div><div></div><div></div><div></div><div></div><div></div><div>3</div></div>	<div><div></div><div></div><div>4</div></div>
5.	<div><div></div><div>1</div></div>	<div><div></div><div></div><div></div><div></div><div></div><div>2</div></div>	<div><div></div><div></div><div></div><div></div><div></div><div>3</div></div>	<div><div></div><div></div><div>4</div></div>
6.	<div><div></div><div>1</div></div>	<div><div></div><div></div><div></div><div></div><div></div><div>2</div></div>	<div><div></div><div></div><div></div><div></div><div></div><div>3</div></div>	<div><div></div><div></div><div>4</div></div>
7.	<div><div></div><div>1</div></div>	<div><div></div><div></div><div></div><div></div><div></div><div>2</div></div>	<div><div></div><div></div><div></div><div></div><div></div><div>3</div></div>	<div><div></div><div></div><div>4</div></div>
8.	<div><div></div><div>1</div></div>	<div><div></div><div></div><div></div><div></div><div></div><div>2</div></div>	<div><div></div><div></div><div></div><div></div><div></div><div>3</div></div>	<div><div></div><div></div><div>4</div></div>
9.	<div><div></div><div>1</div></div>	<div><div></div><div></div><div></div><div></div><div></div><div>2</div></div>	<div><div></div><div></div><div></div><div></div><div></div><div>3</div></div>	<div><div></div><div></div><div>4</div></div>

## AD. SMELL TEST SNIFFIN STICKS

1. Does the subject have a cold or flu now or had one in the past two weeks.

☐

(Answer 0 = NO or 1 = YES)

***IF YES: re-schedule the test for a month after the cold or flu has resolved.***

2. Do you have smell problems (like not being able to smell things properly)?

☐

2.1 When approximately did they start? \_\_\_\_\_years ago

3. Do you have taste problems?

☐

3.1 When approximately did they start? \_\_\_\_\_years ago

4. What is your first language? \_\_\_\_\_

5. Do you speak other languages?

☐

5.1 If yes, which languages: \_\_\_\_\_

## AD. SNIFFIN STICKS SCORING SHEET (1)

Present the fragrant felt tips to the patient one at a time and ask to choose the best fitting smell from the four choices. If the patient cannot decide ask him or her to guess the answer.

1

- |  |  |
|--|--|
| • ORANGE <input style="margin-left: 10px;" type="checkbox"/>     | • STRAWBERRY <input style="margin-left: 10px;" type="checkbox"/> |
| • BLACKBERRY <input style="margin-left: 10px;" type="checkbox"/> | • PINEAPPLE <input style="margin-left: 10px;" type="checkbox"/>  |

2

- |   |   |
|---|---|
| • SMOKE <input style="margin-left: 10px;" type="checkbox"/> | • LEATHER <input style="margin-left: 10px;" type="checkbox"/> |
| • GLUE <input style="margin-left: 10px;" type="checkbox"/>  | • GRASS <input style="margin-left: 10px;" type="checkbox"/>   |

3

- |   |   |
|---|---|
| • HONEY <input style="margin-left: 10px;" type="checkbox"/>   | • CHOCOLATE <input style="margin-left: 10px;" type="checkbox"/> |
| • VANILLA <input style="margin-left: 10px;" type="checkbox"/> | • CINNAMON <input style="margin-left: 10px;" type="checkbox"/>  |

4

- |  |   |
|--|---|
| • CHIVE <input style="margin-left: 10px;" type="checkbox"/>      | • FIR <input style="margin-left: 10px;" type="checkbox"/>   |
| • PEPPERMINT <input style="margin-left: 10px;" type="checkbox"/> | • ONION <input style="margin-left: 10px;" type="checkbox"/> |

5

- |   |  |
|---|--|
| • COCONUT <input style="margin-left: 10px;" type="checkbox"/> | • WALNUT <input style="margin-left: 10px;" type="checkbox"/> |
| • BANANA <input style="margin-left: 10px;" type="checkbox"/>  | • CHERRY <input style="margin-left: 10px;" type="checkbox"/> |

6

- |   |  |
|---|--|
| • PEACH <input style="margin-left: 10px;" type="checkbox"/> | • LEMON <input style="margin-left: 10px;" type="checkbox"/>      |
| • APPLE <input style="margin-left: 10px;" type="checkbox"/> | • GRAPEFRUIT <input style="margin-left: 10px;" type="checkbox"/> |

## AD. SNIFFIN STICKS SCORING SHEET (2)

7

• LIQUORICE ☐

• SPEARMINT ☐

• CHERRY ☐

• COOKIES ☐

8

• MUSTARD ☐

• MENTHOL ☐

• RUBBER ☐

• TURPENTINE ☐

9

• ONION ☐

• GARLIC ☐

• SAUERKRAUT ☐

• CARROTS ☐

10

• CIGARETTES ☐

• WINE ☐

• COFFEE ☐

• SMOKE ☐

11

• MELON ☐

• ORANGE ☐

• PEACH ☐

• APPLE ☐

## AD. SNIFFIN STICKS SCORING SHEET (3)

12

• CLOVES

☐

• CINNAMON

☐

• PEPPER

☐

• MUSTARD

☐

13

• PEAR

☐

• PEACH

☐

• PLUM

☐

• PINEAPPLE

☐

14

• CAMOMILE

☐

• ROSE

☐

• RASPBERRY

☐

• CHERRY

☐

15

• ANISE

☐

• HONEY

☐

• RUM

☐

• FIR

☐

16

• BREAD

☐

• CHEESE

☐

• FISH

☐

• HAM

☐

## AE. UPDRS

### Part I: Non-Motor Aspects of Experiences of Daily Living (nM-EDL) Investigator completed

#### Part I: Non-Motor Aspects of Experiences of Daily Living (nM-EDL)

Overview: This portion of the scale assesses the non-motor impact of Parkinson's disease (PD) on patients' experiences of daily living. There are 13 questions. Part 1A is administered by the rater (six questions) and focuses on complex behaviors. Part 1B is a component of the self-administered Patient Questionnaire that covers seven questions on non-motor experiences of daily living.

##### Part 1A:

In administering Part 1A, the examiner should use the following guidelines:

1. Mark at the top of the form the primary data source as patient, caregiver, or patient and caregiver in equal proportion.
2. The response to each item should refer to a period encompassing the prior week including the day on which the information is collected.
3. All items must have an integer rating (no half points, no missing scores). In the event that an item does not apply or cannot be rated (e.g., amputee who cannot walk), the item is marked UR for Unable to Rate.
4. The answers should reflect the usual level of function and words such as "usually", "generally", "most of the time" can be used with patients.
5. Each question has a text for you to read (Instructions to patients/caregiver). After that statement, you can elaborate and probe based on the target symptoms outlined in the Instructions to examiner. You should NOT READ the RATING OPTIONS to the patient/caregiver, because these are written in medical terminology. From the interview and probing, you will use your medical judgment to arrive at the best response.
6. Patients may have co-morbidities and other medical conditions that can affect their function. You and the patient must rate the problem as it exists and do not attempt to separate elements due to Parkinson's disease from other conditions.

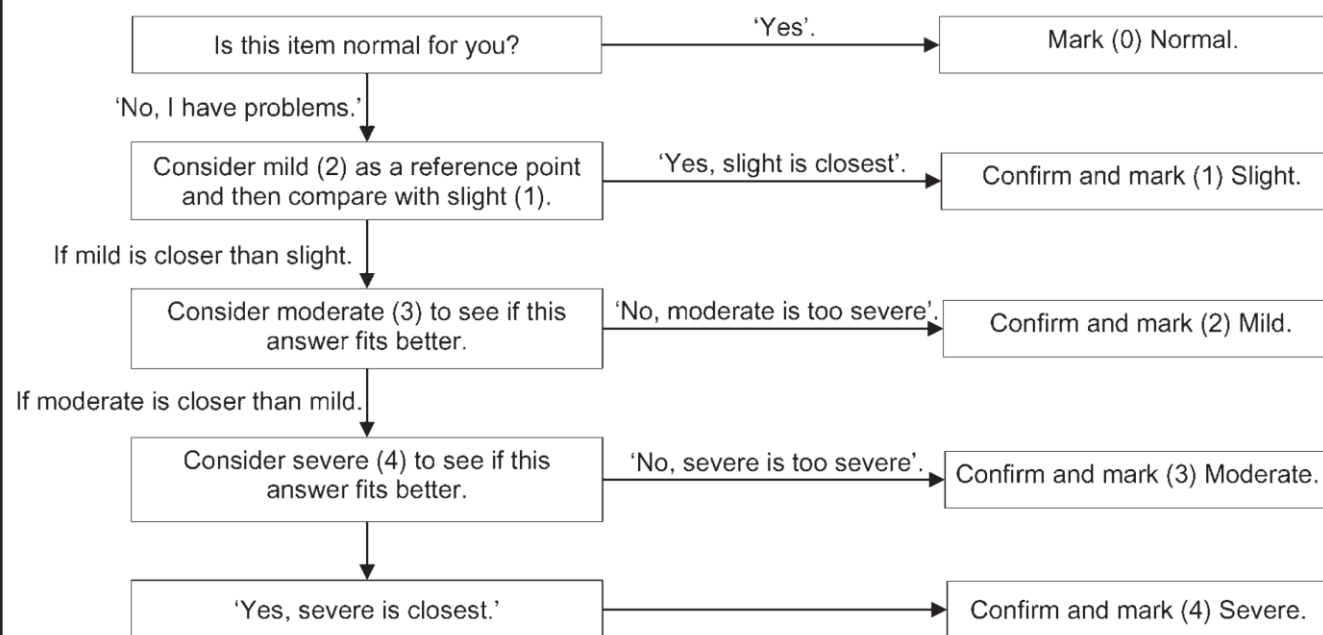
#### EXAMPLE OF NAVIGATING THROUGH THE RESPONSE OPTIONS FOR PART 1A

Suggested strategies for obtaining the most accurate answer:

After reading the instructions to the patient, you will need to probe the entire domain under discussion to determine Normal vs. problematic: If your questions do not identify any problem in this domain, record 0 and move on to the next question.

If your questions identify a problem in this domain, you should work next with a reference anchor at the mid-range (option 2 or Mild) to find out if the patient functions at this level, better or worse. You will not be reading the choices of responses to the patient as the responses use clinical terminology. You will be asking enough probing questions to determine the response that should be coded.

Work up and down the options with the patient to identify the most accurate response, giving a final check by excluding the options above and below the selected response.



## AE. UPDRS

### Part I: Non-Motor Aspects of Experiences of Daily Living (nM-EDL) Investigator completed

## MDS UPDRS

### Part I: Non-Motor Aspects of Experiences of Daily Living (nM-EDL)

#### Part 1A: Complex behaviors: [completed by rater]

Primary source of information:

- ☐ Patient
 ☐ Caregiver
 ☐ Patient and Caregiver in Equal Proportion

To be read to the patient: I am going to ask you six questions about behaviors that you may or may not experience. Some questions concern common problems and some concern uncommon ones. If you have a problem in one of the areas, please choose the best response that describes how you have felt MOST OF THE TIME during the PAST WEEK. If you are not bothered by a problem, you can simply respond NO. I am trying to be thorough, so I may ask questions that have nothing to do with you.

#### 1.1 COGNITIVE IMPAIRMENT

Instructions to examiner: Consider all types of altered level of cognitive function including cognitive slowing, impaired reasoning, memory loss, deficits in attention and orientation. Rate their impact on activities of daily living as perceived by the patient and/or caregiver.

*Instructions to patients [and caregiver]: Over the past week have you had problems remembering things, following conversations, paying attention, thinking clearly, or finding your way around the house or in town? [If yes, examiner asks patient or caregiver to elaborate and probes for information]*

- 0: Normal: No cognitive impairment.
- 1: Slight: Impairment appreciated by patient or caregiver with no concrete interference with the patient's ability to carry out normal activities and social interactions.
- 2: Mild: Clinically evident cognitive dysfunction, but only minimal interference with the patient's ability to carry out normal activities and social interactions.
- 3: Moderate: Cognitive deficits interfere with but do not preclude the patient's ability to carry out normal activities and social interactions.
- 4: Severe: Cognitive dysfunction precludes the patient's ability to carry out normal activities and social interactions.

**SCORE**

## AE. UPDRS

### Part I: Non-Motor Aspects of Experiences of Daily Living (nM-EDL) Investigator completed

	SCORE
<p><b>1.2 HALLUCINATIONS AND PSYCHOSIS</b></p> <p><u>Instructions to examiner:</u> Consider both illusions (misinterpretations of real stimuli) and hallucinations (spontaneous false sensations). Consider all major sensory domains (visual, auditory, tactile, olfactory and gustatory). Determine presence of unformed (for example sense of presence or fleeting false impressions) as well as formed (fully developed and detailed) sensations. Rate the patients insight into hallucinations and identify delusions and psychotic thinking.</p> <p><u>Instructions to patients [and caregiver]:</u> Over the past week have you seen, heard, smelled or felt things that were not really there? [If yes, examiner asks patient or caregiver to elaborate and probes for information]</p> <div style="margin-top: 20px;"> <p>0: Normal:      No hallucinations or psychotic behaviour.</p> <p>1: Slight:        Illusions or non-formed hallucinations, but patient recognizes them without loss of insight.</p> <p>2: Mild:          Formed hallucinations independent of environmental stimuli. No loss of insight.</p> <p>3: Moderate:    Formed hallucinations with loss of insight.</p> <p>4: Severe:        Patient has delusions or paranoia.</p> </div>	<div style="border: 1px solid black; width: 50px; height: 50px; margin: 0 auto;"></div>
<p><b>1.3 DEPRESSED MOOD</b></p> <p><u>Instructions to examiner:</u> Consider low mood, sadness, hopelessness, feelings of emptiness or loss of enjoyment. Determine their presence and duration over the past week and rate their interference with the patient's ability to carry out daily routines and engage in social interactions.</p> <p><u>Instruction to the patient (and caregiver):</u> Over the past week have you felt low, sad, hopeless or unable to enjoy things? If yes, was this feeling for longer than one day at a time? Did it make it difficult for you carry out your usual activities or to be with people? If yes, examiner asks patient or caregiver to elaborate and probes for information]</p> <div style="margin-top: 20px;"> <p>0: Normal:      No depressed mood.</p> <p>1: Slight:        Episodes of depressed mood that are not sustained for more than one day at a time. No interference with patient's ability to carry out normal activities and social interactions.</p> <p>2: Mild:          Depressed mood that is sustained over days, but without interference with normal activities and social interactions.</p> <p>3: Moderate:    Depressed mood that interferes with, but does not preclude, the patient's ability to carry out normal activities and social interactions.</p> <p>4: Severe:        Depressed mood precludes patient's ability to carry out normal activities and social interactions.</p> </div>	<div style="border: 1px solid black; width: 50px; height: 50px; margin: 0 auto;"></div>



**AE. UPDRS**  
**PART I: NON-MOTOR ASPECTS OF EXPERIENCES OF DAILY LIVING**  
**(NM-EDL) INVESTIGATOR COMPLETED**

	<b>SCORE</b>
<p><b>1.4 ANXIOUS MOOD</b></p> <p><u>Instructions to examiner:</u> Determine nervous, tense, worried or anxious feelings (including panic attacks) over the past week and rate their duration and interference with the patient's ability to carry out daily routines and engage in social interactions.</p> <p><u>Instructions to patients [and caregiver]:</u> Over the past week have you felt nervous, worried or tense? If yes, was this feeling for longer than one day at a time? Did it make it difficult for you to follow your usual activities or to be with other people? [If yes, examiner asks patient or caregiver to elaborate and probes for information.]</p> <p>0: Normal: No anxious feelings.</p> <p>1: Slight: Anxious feelings present but not sustained for more than one day at a time. No interference with patient's ability to carry out normal activities and social interactions.</p> <p>2: Mild: Anxious feelings are sustained over more than one day at a time, but without interference with patient's ability to carry out normal activities and social interactions.</p> <p>3: Moderate: Anxious feelings interfere with, but do not preclude, the patient's ability to carry out normal activities and social interactions.</p> <p>4: Severe: Anxious feelings preclude patient's ability to carry out normal activities and social interactions.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>
<p><b>1.5 APATHY</b></p> <p><u>Instructions to examiner:</u> Consider level of spontaneous activity, assertiveness, motivation and initiative and rate the impact of reduced levels on performance of daily routines and social interactions. Here the examiner should attempt to distinguish between apathy and similar symptoms that are best explained by depression.</p> <p><u>Instructions to patients (and caregiver):</u> Over the past week, have you felt indifferent to doing activities or being with people? If yes, examiner asks patient or caregiver to elaborate and probes for information.]</p> <p>0: Normal: No apathy.</p> <p>1: Slight: Apathy appreciated by patient and/or caregiver, but no interference with daily activities and social interactions.</p> <p>2: Mild: Apathy interferes with isolated activities and social interactions.</p> <p>3: Moderate: Apathy interferes with most activities and social interactions.</p> <p>4: Severe: Passive and withdrawn, complete loss of initiative.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>

# AE. UPDRS

## PART I: NON-MOTOR ASPECTS OF EXPERIENCES OF DAILY LIVING (NM-EDL) INVESTIGATOR COMPLETED

1.6 FEATURES OF DOPAMINE DYSREGULATION SYNDROME	SCORE
<p><u>Instructions to examiner:</u> Consider involvement in a variety of activities including atypical or excessive gambling (e.g. casinos or lottery tickets), atypical or excessive sexual drive or interests (e.g., unusual interest in pornography, masturbation, sexual demands on partner), other repetitive activities (e.g. hobbies, dismantling objects, sorting or organizing), or taking extra non-prescribed medication for non-physical reasons (i.e., addictive behavior). Rate the impact of such abnormal activities/behaviors on the patient's personal life and on his family and social relations (including need to borrow money or other financial difficulties like withdrawal of credit cards, major family conflicts, lost time from work, or missed meals or sleep because of the activity).</p> <p><u>Instructions to patients [and caregiver]:</u> Over the past week, have you had unusually strong urges that are hard to control? Do you feel driven to do or think about something and find it hard to stop? [Give patient examples such as gambling, cleaning, using the computer, taking extra medicine, obsessing about food or sex, all depending on the patients.</p> <div style="display: flex; justify-content: space-between;"> <div style="width: 70%;"> <p>0: Normal:      No problems present.</p> <p>1: Slight:       Problems are present but usually do not cause any difficulties for the patient or family/caregiver.</p> <p>2: Mild:         Problems are present and usually cause a few difficulties in the patient's personal and family life.</p> <p>3: Moderate:   Problems are present and usually cause a lot of difficulties in the patient's personal and family life.</p> <p>4: Severe:      Problems are present and preclude the patient's ability to carry out normal activities or social interactions or to maintain previous standards in personal and family life.</p> </div> <div style="width: 25%; text-align: center; border: 1px solid black; height: 100px; margin-top: 20px;"></div> </div>	

## AF. UPDRS PART III: MOTOR EXAMINATION

### Part III: Motor Examination

Overview: This portion of the scale assesses the motor signs of PD. In administering Part III of the MDS-UPDRS the examiner should comply with the following guidelines:

At the top of the form, mark whether the patient is on medication for treating the symptoms of Parkinson's disease and, if on levodopa, the time since the last dose.

Also, if the patient is receiving medication for treating the symptoms of Parkinson's Disease, mark the patient's clinical state using the following definitions:

**ON** is the typical functional state when patients are receiving medication and have a good response.

**OFF** is the typical functional state when patients have a poor response in spite of taking medications.

The investigator should "rate what you see". Admittedly, concurrent medical problems such as stroke, paralysis, arthritis, contracture, and orthopedic problems such as hip or knee replacement and scoliosis may interfere with individual items in the motor examination. In situations where it is absolutely impossible to test (e.g., amputations, plegia, limb in a cast), use the notation "**UR**" for Unable to Rate. Otherwise, rate the performance of each task as the patient performs in the context of co-morbidities.

All items must have an integer rating (no half points, no missing ratings).

Specific instructions are provided for the testing of each item. These should be followed in all instances. The investigator demonstrates while describing tasks the patient is to perform and rates function immediately thereafter. For Global Spontaneous Movement and Rest Tremor items (3.14 and 3.17), these items have been placed purposefully at the end of the scale because clinical information pertinent to the score will be obtained throughout the entire examination.

At the end of the rating, indicate if dyskinesia (chorea or dystonia) was present at the time of the examination, and if so, whether these movements interfered with the motor examination.

**3a** Is the patient on medication for treating the symptoms of Parkinson's Disease? ☐ No ☐ Yes

**3b** If the patient is receiving medication for treating the symptoms of Parkinson's Disease, mark the patient's clinical state using the following definitions:

☐ ON: On is the typical functional state when patients are receiving medication and have a good response.

☐ OFF: Off is the typical functional state when patients have a poor response in spite of taking medications.

**3c** Is the patient on Levodopa ? ☐ No ☐ Yes

**3.C1** If yes, minutes since last levodopa dose: \_\_\_\_\_

## AF. UPDRS PART III: MOTOR EXAMINATION

	<b>SCORE</b>
<p><b>3.1 SPEECH</b></p> <p><u>Instructions to examiner:</u> Listen to the patient's free-flowing speech and engage in conversation if necessary. Suggested topics: ask about the patient's work, hobbies, exercise, or how he got to the doctor's office. Evaluate volume, modulation (prosody) and clarity, including slurring, palilalia (repetition of syllables) and tachyphemia (rapid speech, running syllables together).</p> <p>0: Normal: No speech problems.</p> <p>1: Slight: Loss of modulation, diction or volume, but still all words easy to understand.</p> <p>2: Mild: Loss of modulation, diction, or volume, with a few words unclear, but the overall sentences easy to follow.</p> <p>3: Moderate: Speech is difficult to understand to the point that some, but not most, sentences are poorly understood.</p> <p>4: Severe: Most speech is difficult to understand or unintelligible.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>
<p><b>3.2 FACIAL EXPRESSION</b></p> <p><u>Instructions to examiner:</u> Observe the patient sitting at rest for 10 seconds, without talking and also while talking. Observe eye-blink frequency, masked facies or loss of facial expression, spontaneous smiling and parting of lips.</p> <p>0: Normal: Normal facial expression.</p> <p>1: Slight: Minimal masked facies manifested only by decreased frequency of blinking.</p> <p>2: Mild: In addition to decreased eye-blink frequency, Masked facies present in the lower face as well, namely fewer movements around the mouth, such as less spontaneous smiling, but lips not parted.</p> <p>3: Moderate: Masked facies with lips parted some of the time when the mouth is at rest.</p> <p>4: Severe: Masked facies with lips parted most of the time when the mouth is at rest.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>

## AF. UPDRS

### PART III: MOTOR EXAMINATION

	<b>SCORE</b>
<b>3.3 RIGIDITY</b>	
<p><u>Instructions to examiner:</u> Rigidity is judged on slow passive movement of major joints with the patient in a relaxed position and the examiner manipulating the limbs and neck. First, test without an activation maneuver. Test and rate neck and each limb separately. For arms, test the wrist and elbow joints simultaneously. For legs, test the hip and knee joints simultaneously. If no rigidity is detected, use an activation maneuver such as tapping fingers, fist opening/closing, or heel tapping in a limb not being tested. Explain to the patient to go as limp as possible as you test for rigidity.</p>	<div style="border: 1px solid black; width: 50px; height: 50px; margin: 0 auto;"></div> <p>Neck</p>
<p>0: Normal: No rigidity.</p>	<div style="border: 1px solid black; width: 50px; height: 50px; margin: 0 auto;"></div>
<p>1: Slight: Rigidity only detected with activation maneuver.</p>	<p>RUE</p>
<p>2: Mild: Rigidity detected without the activation maneuver, but full range of motion is easily achieved.</p>	<div style="border: 1px solid black; width: 50px; height: 50px; margin: 0 auto;"></div>
<p>3: Moderate: Rigidity detected without the activation maneuver; full range of motion is achieved with effort.</p>	<p>LUE</p>
<p>4: Severe: Rigidity detected without the activation maneuver and full range of motion not achieved.</p>	<div style="border: 1px solid black; width: 50px; height: 50px; margin: 0 auto;"></div> <p>RLE</p>
	<div style="border: 1px solid black; width: 50px; height: 50px; margin: 0 auto;"></div> <p>LLE</p>
<b>3.4 FINGER TAPPING</b>	
<p><u>Instructions to examiner:</u> Each hand is tested separately. Demonstrate the task, but do not continue to perform the task while the patient is being tested. Instruct the patient to tap the index finger on the thumb 10 times as quickly AND as big as possible. Rate each side separately, evaluating speed, amplitude, hesitations, halts and decrementing amplitude.</p>	
<p>0: Normal: No problems.</p>	<div style="border: 1px solid black; width: 50px; height: 50px; margin: 0 auto;"></div>
<p>1: Slight: Any of the following: a) the regular rhythm is broken with one or two interruptions or hesitations of the tapping movement; b) slight slowing; c) the amplitude decrements near the end of the 10 taps.</p>	<p>R</p>
<p>2: Mild: Any of the following: a) 3 to 5 interruptions during tapping; b) mild slowing; c) the amplitude decrements midway in the 10-tap sequence.</p>	<div style="border: 1px solid black; width: 50px; height: 50px; margin: 0 auto;"></div>
<p>3: Moderate: Any of the following: a) more than 5 interruptions during tapping or at least one longer arrest (freeze) in ongoing movement; b) moderate slowing; c) the amplitude decrements starting after the 1st tap.</p>	<p>L</p>
<p>4: Severe: Cannot or can only barely perform the task because of slowing, interruptions or decrements.</p>	



## AF. UPDRS

### PART III: MOTOR EXAMINATION

	<b>SCORE</b>
<p><b>3.5 HAND MOVEMENTS</b></p> <p><u>Instructions to examiner:</u> Test each hand separately. Demonstrate the task, but do not continue to perform the task while the patient is being tested. Instruct the patient to make a tight fist with the arm bent at the elbow so that the palm faces the examiner. Have the patient open the hand 10 times as fully AND as quickly as possible. If the patient fails to make a tight fist or to open the hand fully, remind him/her to do so. Rate each side separately, evaluating speed, amplitude, hesitations, halts and decrementing amplitude.</p> <p>0: Normal: No problem.</p> <p>1: Slight: Any of the following: a) the regular rhythm is broken with one or two interruptions or hesitations of the movement; b) slight slowing; c) the amplitude decrements near the end of the task.</p> <p>2: Mild: Any of the following: a) 3 to 5 interruptions during the movements; b) mild slowing; c) the amplitude decrements midway in the task.</p> <p>3: Moderate: Any of the following: a) more than 5 interruptions during the movement or at least one longer arrest (freeze) in ongoing movement; b) moderate slowing; c) the amplitude decrements starting after the 1st open-and-close sequence.</p> <p>4: Severe: Cannot or can only barely perform the task because of slowing, interruptions or decrements.</p>	<div style="border: 1px solid black; width: 50px; height: 50px; margin: 10px auto;"></div> <p>R</p> <div style="border: 1px solid black; width: 50px; height: 50px; margin: 10px auto;"></div> <p>L</p>
<p><b>3.6 PRONATION-SUPINATION MOVEMENTS OF HANDS</b></p> <p><u>Instructions to examiner:</u> Test each hand separately. Demonstrate the task, but do not continue to perform the task while the patient is being tested. Instruct the patient to extend the arm out in front of his/her body with the palms down; then to turn the palm up and down alternately 10 times as fast and as fully as possible. Rate each side separately, evaluating speed, amplitude, hesitations, halts and decrementing amplitude.</p> <p>0: Normal: No problems.</p> <p>1: Slight: Any of the following: a) the regular rhythm is broken with one or two interruptions or hesitations of the movement; b) slight slowing; c) the amplitude decrements near the end of the sequence.</p> <p>2: Mild: Any of the following: a) 3 to 5 interruptions during the movements; b) mild slowing; c) the amplitude decrements midway in the sequence.</p> <p>3: Moderate: Any of the following: a) more than 5 interruptions during the movement or at least one longer arrest (freeze) in ongoing movement; b) moderate slowing c) the amplitude decrements starting after the 1st supination-pronation sequence.</p> <p>4: Severe: Cannot or can only barely perform the task because of slowing, interruptions or decrements.</p>	<div style="border: 1px solid black; width: 50px; height: 50px; margin: 10px auto;"></div> <p>R</p> <div style="border: 1px solid black; width: 50px; height: 50px; margin: 10px auto;"></div> <p>L</p>

## AF. UPDRS

### PART III: MOTOR EXAMINATION

	<b>SCORE</b>
<p><b>3.7 TOE TAPPING</b></p> <p><u>Instructions to examiner:</u> Have the patient sit in a straight-backed chair with arms, both feet on the floor. Test each foot separately. Demonstrate the task, but do not continue to perform the task while the patient is being tested. Instruct the patient to place the heel on the ground in a comfortable position and then tap the toes 10 times as big and as fast as possible. Rate each side separately, evaluating speed, amplitude, hesitations, halts and decrementing amplitude.</p> <p>0: Normal:      No problem.</p> <p>1: Slight:        Any of the following: a) the regular rhythm is broken with one or two interruptions or hesitations of the tapping movement; b) slight slowing; c) amplitude decrements near the end of the ten taps.</p> <p>2: Mild:          Any of the following: a) 3 to 5 interruptions during the tapping movements; b) mild slowing; c) amplitude decrements midway in the task.</p> <p>3: Moderate:    Any of the following: a) more than 5 interruptions during the tapping movements or at least one longer arrest (freeze) in ongoing movement; b) moderate slowing; c) amplitude decrements after the first tap.</p> <p>4: Severe:       Cannot or can only barely perform the task because of slowing, interruptions or decrements.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 10px auto;"></div> <p>R</p> <div style="border: 1px solid black; width: 40px; height: 40px; margin: 10px auto;"></div> <p>L</p>
<p><b>3.8 LEG AGILITY</b></p> <p><u>Instructions to examiner:</u> Have the patient sit in a straight-backed chair with arms. The patient should have both feet comfortably on the floor. Test each leg separately. Demonstrate the task, but do not continue to perform the task while the patient is being tested. Instruct the patient to place the foot on the ground in a comfortable position and then raise and stomp the foot on the ground 10 times as high and as fast as possible. Rate each side separately, evaluating speed, amplitude, hesitations, halts and decrementing amplitude.</p> <p>0: Normal:        No problems.</p> <p>1: Slight:        Any of the following: a) the regular rhythm is broken with one or two interruptions or hesitations of the movement; b) slight slowing; c) amplitude decrements near the end of the task.</p> <p>2: Mild:          Any of the following: a) 3 to 5 interruptions during the movements; b) mild slowness; c) amplitude decrements midway in the task.</p> <p>3: Moderate:    Any of the following: a) more than 5 interruptions during the movement or at least one longer arrest (freeze) in ongoing movement; b) moderate slowing in speed; c) amplitude decrements after the first tap.</p> <p>4: Severe:       Cannot or can only barely perform the task because of slowing, interruptions or decrements.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 10px auto;"></div> <p>R</p> <div style="border: 1px solid black; width: 40px; height: 40px; margin: 10px auto;"></div> <p>L</p>

## AF. UPDRS

### PART III: MOTOR EXAMINATION

	<b>SCORE</b>
<p><b>3.9 ARISING FROM CHAIR</b></p> <p>Instructions to examiner: Have the patient sit in a straight-backed chair with arms, with both feet on the floor and sitting back in the chair (if the patient is not too short). Ask the patient to cross his/her arms across the chest and then to stand up. If the patient is not successful, repeat this attempt a maximum up to two more times. If still unsuccessful, allow the patient to move forward in the chair to arise with arms folded across the chest. Allow only one attempt in this situation. If unsuccessful, allow the patient to push off using his/her hands on the arms of the chair. Allow a maximum of three trials of pushing off. If still not successful, assist the patient to arise. After the patient stands up, observe the posture for item 3.13</p> <p>0: Normal:           No problems. Able to arise quickly without hesitation.</p> <p>1: Slight:            Arising is slower than normal; or may need more than one attempt; or may need to move forward in the chair to arise. No need to use the arms of the chair.</p> <p>2: Mild:             Pushes self up from arms of chair without difficulty.</p> <p>3: Moderate:        Needs to push off, but tends to fall back; or may have to try more than one time using arms of chair, but can get up without help.</p> <p>4: Severe:           Unable to arise without help.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>
<p><b>3.10 GAIT</b></p> <p>Instructions to examiner: Testing gait is best performed by having the patient walking away from and towards the examiner so that both right and left sides of the body can be easily observed simultaneously. The patient should walk at least 10 meters (30 feet), then turn around and return to the examiner. This item measures multiple behaviors: stride amplitude, stride speed, height of foot lift, heel strike during walking, turning, and arm swing, but not freezing. Assess also for "freezing of gait" (next item 3.11) while patient is walking. Observe posture for item 3.13</p> <p>0: Normal:           No problems.</p> <p>1: Slight:            Independent walking with minor gait impairment.</p> <p>2: Mild:             Independent walking but with substantial gait impairment.</p> <p>3: Moderate:        Requires an assistance device for safe walking (walking stick, walker) but not a person.</p> <p>4: Severe:           Cannot walk at all or only with another person's assistance.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>



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### PART III: MOTOR EXAMINATION

	<b>SCORE</b>
<p><b>3.11 FREEZING OF GAIT</b></p> <p><u>Instructions to examiner:</u> While assessing gait, also assess for the presence of any gait freezing episodes. Observe for start hesitation and stuttering movements especially when turning and reaching the end of the task. To the extent that safety permits, patients may NOT use sensory tricks during the assessment.</p> <p>0: Normal:        No freezing.</p> <p>1: Slight:        Freezes on starting, turning or walking through doorway with a single halt during any of these events, but then continues smoothly without freezing during straight walking.</p> <p>2: Mild:         Freezes on starting, turning or walking through doorway with more than one halt during any of these activities, but continues smoothly without freezing during straight walking.</p> <p>3: Moderate:     Freezes once during straight walking.</p> <p>4: Severe:        Freezes multiple times during straight walking.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>
<p><b>3.12 POSTURAL STABILITY</b></p> <p><u>Instructions to examiner:</u> The test examines the response to sudden body displacement produced by a <u>quick, forceful</u> pull on the shoulders while the patient is standing erect with eyes open and feet comfortably apart and parallel to each other. Test retropulsion. Stand behind the patient and instruct the patient on what is about to happen. Explain that s/he is allowed to take a step backwards to avoid falling. There should be a solid wall behind the examiner, at least 1-2 meters away to allow for the observation of the number of retropulsive steps. The first pull is an instructional demonstration and is purposely milder and not rated. The second time the shoulders are pulled briskly and forcefully towards the examiner with enough force to displace the center of gravity so that patient <b>MUST</b> take a step backwards. The examiner needs to be ready to catch the patient, but must stand sufficiently back so as to allow enough room for the patient to take several steps to recover independently. Do not allow the patient to flex the body abnormally forward in anticipation of the pull. Observe for the number of steps backwards or falling. Up to and including two steps for recovery is considered normal, so abnormal ratings begin with three steps. If the patient fails to understand the test, the examiner can repeat the test so that the rating is based on an assessment that the examiner feels reflects the patient's limitations rather than misunderstanding or lack of preparedness. Observe standing posture for item 3.13</p> <p>0: Normal:        No problems: Recovers with one or two steps.</p> <p>1: Slight:        3-5 steps, but subject recovers unaided.</p> <p>2: Mild:         More than 5 steps, but subject recovers unaided.</p> <p>3: Moderate:     Stands safely, but with absence of postural response; falls if not caught by examiner.</p> <p>4: Severe:        Very unstable, tends to lose balance spontaneously or with just a gentle pull on the shoulders.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>

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### PART III: MOTOR EXAMINATION

	<b>SCORE</b>
<p><b>3.13 POSTURE</b></p> <p>Instructions to examiner: Posture is assessed with the patient standing erect after arising from a chair, during walking, and while being tested for postural reflexes. If you notice poor posture, tell the patient to stand up straight and see if the posture improves (see option 2 below). Rate the worst posture seen in these three observation points. Observe for flexion and side-to-side leaning.</p> <p>0: Normal:      No problems.</p> <p>1: Slight:      Not quite erect, but posture could be normal for older person.</p> <p>2: Mild:      Definite flexion, scoliosis or leaning to one side, but patient can correct posture to normal posture when asked to do so.</p> <p>3: Moderate:      Stooped posture, scoliosis or leaning to one side that cannot be corrected volitionally to a normal posture by the patient.</p> <p>4: Severe:      Flexion, scoliosis or leaning with extreme abnormality of posture.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>
<p><b>3.14 GLOBAL SPONTANEITY OF MOVEMENT (BODY BRADYKINESIA)</b></p> <p>Instructions to examiner: This global rating combines all observations on slowness, hesitancy, and small amplitude and poverty of movement in general, including a reduction of gesturing and of crossing the legs. This assessment is based on the examiner's global impression after observing for spontaneous gestures while sitting, and the nature of arising and walking.</p> <p>0: Normal:      No problems.</p> <p>1: Slight:      Slight global slowness and poverty of spontaneous movements.</p> <p>2: Mild:      Mild global slowness and poverty of spontaneous movements.</p> <p>3: Moderate:      Moderate global slowness and poverty of spontaneous movements.</p> <p>4: Severe:      Severe global slowness and poverty of spontaneous movements.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>
<p><b>3.15 POSTURAL TREMOR OF THE HANDS</b></p> <p>Instructions to examiner: All tremor, including re-emergent rest tremor, that is present in this posture is to be included in this rating. Rate each hand separately. Rate the highest amplitude seen. Instruct the patient to stretch the arms out in front of the body with palms down. The wrist should be straight and the fingers comfortably separated so that they do not touch each other. Observe this posture for 10 seconds.</p> <p>0: Normal:      No tremor.</p> <p>1: Slight:      Tremor is present but less than 1 cm in amplitude.</p> <p>2: Mild:      Tremor is at least 1 but less than 3 cm in amplitude.</p> <p>3: Moderate:      Tremor is at least 3 but less than 10 cm in amplitude.</p> <p>4: Severe:      Tremor is at least 10 cm in amplitude.</p>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto; margin-bottom: 10px;"></div> <div style="text-align: center;">R</div> <div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div> <div style="text-align: center;">L</div>

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### PART III: MOTOR EXAMINATION

	<b>SCORE</b>
<p><b>3.16 KINETIC TREMOR OF THE HANDS</b></p> <p><u>Instructions to examiner:</u> This is tested by the finger-to-nose maneuver. With the arm starting from the outstretched position, have the patient perform at least three finger-to-nose maneuvers with each hand reaching as far as possible to touch the examiner's finger. The finger-to-nose maneuver should be performed slowly enough not to hide any tremor that could occur with very fast arm movements. Repeat with the other hand, rating each hand separately. The tremor can be present throughout the movement or as the tremor reaches either target (nose or finger). Rate the highest amplitude seen.</p> <p>0: Normal:           No tremor.</p> <p>1: Slight:            Tremor is present but less than 1 cm in amplitude.</p> <p>2: Mild:             Tremor is at least 1 but less than 3 cm in amplitude.</p> <p>3: Moderate:        Tremor is at least 3 but less than 10 cm in amplitude.</p> <p>4: Severe:          Tremor is at least 10 cm in amplitude.</p>	<div style="border: 1px solid black; width: 50px; height: 50px; margin: 0 auto; margin-bottom: 10px;"></div> <div>R</div> <div style="border: 1px solid black; width: 50px; height: 50px; margin: 0 auto; margin-bottom: 10px;"></div> <div>L</div>
<p><b>3.17 REST TREMOR AMPLITUDE</b></p> <p><u>Instructions to examiner:</u> This and the next item have been placed purposefully at the end of the examination to allow the rater to gather observations on rest tremor that may appear at any time during the exam, including when quietly sitting, during walking and during activities when some body parts are moving but others are at rest. Score the maximum amplitude that is seen at any time as the final score. Rate only the amplitude and not the persistence or the intermittency of the tremor. As part of this rating, the patient should sit quietly in a chair with the hands placed on the arms of the chair (not in the lap) and the feet comfortably supported on the floor for 10 seconds with no other directives. Rest tremor is assessed separately for all four limbs and also for the lip/jaw. Rate only the maximum amplitude that is seen at any time as the final rating.</p> <p>Extremity ratings</p> <p>0: Normal:           No tremor.</p> <p>1: Slight.:           &lt; 1 cm in maximal amplitude.</p> <p>2: Mild:             &gt; 1 cm but &lt; 3 cm in maximal amplitude.</p> <p>3: Moderate:        3 - 10 cm in maximal amplitude.</p> <p>4: Severe:          &gt; 10 cm in maximal amplitude.</p> <p>Lip/Jaw ratings</p> <p>0: Normal:           No tremor.</p> <p>1: Slight:            &lt; 1 cm in maximal amplitude.</p> <p>2: Mild:             &gt; 1 cm but &lt; 2 cm in maximal amplitude.</p> <p>3: Moderate:        &gt; 2 cm but &lt; 3 cm in maximal amplitude.</p> <p>4: Severe:          &gt; 3 cm in maximal amplitude.</p>	<div style="border: 1px solid black; width: 50px; height: 50px; margin: 0 auto; margin-bottom: 10px;"></div> <div>RUE</div> <div style="border: 1px solid black; width: 50px; height: 50px; margin: 0 auto; margin-bottom: 10px;"></div> <div>LUE</div> <div style="border: 1px solid black; width: 50px; height: 50px; margin: 0 auto; margin-bottom: 10px;"></div> <div>RLE</div> <div style="border: 1px solid black; width: 50px; height: 50px; margin: 0 auto; margin-bottom: 10px;"></div> <div>LLE</div> <div style="border: 1px solid black; width: 50px; height: 50px; margin: 0 auto; margin-bottom: 10px;"></div> <div>Lip/Jaw</div>

## AF. UPDRS

**SCORE**

7

- 7

A. Were dyskinesias (chorea or dystonia) present during examination? ☐ No ☐ Yes

B. If yes, did these movements interfere with your ratings? ☐ No ☐ Yes

7

- 7



## AG. UPDRS PART IV: MOTOR COMPLICATIONS

### Part IV: Motor Complications

**Overview and Instructions:** In this section, the rater uses historical and objective information to assess two motor complications, dyskinesias and motor fluctuations that include OFF-state dystonia. Use all information from patient, caregiver, and the examination to answer the six questions that summarize function over the past week including today. As in the other sections, rate using only integers (no half points allowed) and leave no missing ratings. If the item cannot be rated, place UR for Unable to Rate. You will need to choose some answers based on percentages, and therefore you will need to establish how many hours generally are awake hours and use this figure as the denominator for "OFF" time and Dyskinesias. For "OFF dystonia", the total "Off" time will be the denominator. Operational definitions for examiner's use.

**Dyskinesias:** Involuntary random movements

Words that patients often recognize for dyskinesias include "irregular jerking", "wiggling", "twitching". It is essential to stress to the patient the difference between dyskinesias and tremor, a common error when patients are assessing dyskinesias.

**Dystonia:** contorted posture, often with a twisting component:

Words that patients often recognize for dystonia include "spasms", "cramps", "posture".

**Motor fluctuation:** Variable response to medication:

Words that patients often recognize for motor fluctuation include "wearing out", "wearing off", "roller-coaster effect", "on-off", "uneven medication effects".

**OFF:** Typical functional state when patients have a poor response in spite of taking medication or the typical functional response when patients are on NO treatment for parkinsonism. Words that patients often recognize include "low time", "bad time", "shaking time", "slow time", "time when my medications don't work."

**ON:** Typical functional state when patients are receiving medication and have a good response:

Words that patients often recognize include "good time", "walking time", "time when my medications work."

#### A . DYSKINESIAS [exclusive of OFF-state dystonia]

##### 4.1 TIME SPENT WITH DYSKINESIAS

Instructions to examiner: Determine the hours in the usual waking day and then the hours of dyskinesias. Calculate the percentage. If the patient has dyskinesias in the office, you can point them out as a reference to ensure that patients and caregivers understand what they are rating. You may also use your own acting skills to enact the dyskinetic movements you have seen in the patient before or show them dyskinetic movements typical of other patients. Exclude from this question early morning and nighttime painful dystonia.

*Instructions to patient [and caregiver]. Over the past week, how many hours do you usually sleep on a daily basis, including nighttime sleep and daytime napping? Alright, if you sleep \_\_\_\_ hrs, you are awake \_\_\_\_ hrs. Out of those awake hours, how many hours in total do you have wiggling, twitching or jerking movements? Do not count the times when you have tremor, which is a regular back and forth shaking or times when you have painful foot cramps or spasms in the early morning or at nighttime. I will ask about those later. Concentrate only on these types of wiggling, jerking and irregular movements. Add up all the time during the waking day when these usually occur. How many hours \_\_\_\_ (use this number for your calculation).*

**SCORE**



0: Normal: No dyskinesias.

1: Slight: ≤ 25% of waking day.

2: Mild: 26 - 50% of waking day.

3: Moderate: 51 - 75% of waking day.

4: Severe: > 75% of waking day.

1. Total Hours Awake: \_\_\_\_\_

2. Total Hours with Dyskinesia: \_\_\_\_\_

3. % Dyskinesia = ((2/1)\*100): \_\_\_\_\_

## AG. UPDRS

### PART IV: MOTOR COMPLICATIONS

4.2 FUNCTIONAL IMPACT OF DYSKINESIAS	SCORE
<p>Instructions to examiner: Determine the degree to which dyskinesias impact on the patient's daily function in terms of activities and social interactions. Use the patient's and caregiver's response to your question and your own observations during the office visit to arrive at the best answer.</p> <p><i>Instructions to patient [and caregiver]: Over the past week, did you usually have trouble doing things or being with people when these jerking movements occurred? Did they stop you from doing things or from being with people?</i></p> <div style="margin-top: 10px;"> <p>0: Normal:           No dyskinesias or no impact by dyskinesias on activities or social interactions.</p> <p>1: Slight:           Dyskinesias impact on a few activities, but the patient usually performs all activities and participates in all social interactions during dyskinetic periods.</p> <p>2: Mild:            Dyskinesias impact on many activities, but the patient usually performs all activities and participates in all social interactions during dyskinetic periods.</p> <p>3: Moderate:       Dyskinesias impact on activities to the point that the patient usually does not perform some activities or does not usually participate in some social activities during dyskinetic episodes.</p> <p>4: Severe:          Dyskinesias impact on function to the point that the patient usually does not perform most activities or participate in most social interactions during dyskinetic episodes.</p> </div>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>
<b>B . MOTOR FLUCTUATIONS</b>	
<p><b>4.3 TIME SPENT IN THE OFF STATE</b></p> <p>Instructions to examiner: Use the number of waking hours derived from 4.1 and determine the hours spent in the "OFF" state. Calculate the percentage. If the patient has an OFF period in the office, you can point to this state as a reference. You may also use your knowledge of the patient to describe a typical OFF period. Additionally you may use your own acting skills to enact an OFF period you have seen in the patient before or show them OFF function typical of other patients. Mark down the typical number of OFF hours, because you will need this number for completing 4.6</p> <p><i>Instructions to patient [and caregiver]: Some patients with Parkinson's disease have a good effect from their medications throughout their awake hours and we call that "ON" time. Other patients take their medications but still have some hours of low time, bad time, slow time or shaking time. Doctors call these low periods "OFF" time. Over the past week, you told me before that you are generally awake ____ hrs each day. Out of these awake hours, how many hours in total do you usually have this type of low level or OFF function ____ (Use this number for your calculations).</i></p> <div style="margin-top: 10px;"> <p>0: Normal:           No OFF time.</p> <p>1: Slight:           ≤ 25% of waking day.</p> <p>2: Mild:            26 - 50% of waking day.</p> <p>3: Moderate:       51 - 75% of waking day.</p> <p>4: Severe:          &gt; 75% of waking day.</p> </div>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>
<div style="display: flex; justify-content: space-between; align-items: flex-start;"> <div style="width: 45%;"> <p>1. Total Hours Awake: _____</p> <p>2. Total Hours OFF: _____</p> <p>3. % OFF = ((2/1)*100): _____</p> </div> <div style="width: 50%;"></div> </div>	



## AG. UPDRS

### PART IV: MOTOR COMPLICATIONS

	<b>SCORE</b>
<p><b>4.4 FUNCTIONAL IMPACT OF FLUCTUATIONS</b></p> <p><u>Instructions to examiner:</u> Determine the degree to which motor fluctuations impact on the patient's daily function in terms of activities and social interactions. This question concentrates on the difference between the ON state and the OFF state. If the patient has no OFF time, the rating must be 0, but if patients have very mild fluctuations, it is still possible to be rated 0 on this item if no impact on activities occurs. Use the patient's and caregiver's response to your question and your own observations during the office visit to arrive at the best answer.</p> <p><u>Instructions to patient [and caregiver]:</u> Think about when those low or "OFF" periods have occurred over the past week. Do you usually have more problems doing things or being with people than compared to the rest of the day when you feel your medications working? Are there some things you usually do during a good period that you have trouble with or stop doing during a low period?</p> <div style="margin-top: 20px;"> <div style="display: flex; justify-content: space-between; padding: 0 10px;"> <div style="width: 15%;">0: Normal:</div> <div>No fluctuations or No impact by fluctuations on performance of activities or social interactions.</div> </div> <div style="margin-top: 10px;"> <div style="display: flex; justify-content: space-between; padding: 0 10px;"> <div style="width: 15%;">1: Slight:</div> <div>Fluctuations impact on a few activities, but during OFF, the patient usually performs all activities and participates in all social interactions that typically occur during the ON state.</div> </div> <div style="margin-top: 10px;"> <div style="display: flex; justify-content: space-between; padding: 0 10px;"> <div style="width: 15%;">2: Mild:</div> <div>Fluctuations impact many activities, but during OFF, the patient still usually performs all activities and participates in all social interactions that typically occur during the ON state.</div> </div> <div style="margin-top: 10px;"> <div style="display: flex; justify-content: space-between; padding: 0 10px;"> <div style="width: 15%;">3: Moderate:</div> <div>Fluctuations impact on the performance of activities during OFF to the point that the patient usually does not perform some activities or participate in some social interactions that are performed during ON periods.</div> </div> <div style="margin-top: 10px;"> <div style="display: flex; justify-content: space-between; padding: 0 10px;"> <div style="width: 15%;">4: Severe:</div> <div>Fluctuations impact on function to the point that, during OFF, the patient usually does not perform most activities or participate in most social interactions that are performed during ON periods.</div> </div> </div> </div> </div> </div> </div>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>
<p><b>4.5 COMPLEXITY OF MOTOR FLUCTUATIONS</b></p> <p><u>Instructions to examiner:</u> Determine the usual predictability of OFF function whether due to dose, time of day, food intake or other factors. Use the information provided by the patients and caregiver and supplement with your own observations. You will ask if the patient can count on them always coming at a special time, mostly coming at a special time (in which case you will probe further to separate slight from mild), only sometimes coming at a special time or are they totally unpredictable? Narrowing down the percentage will allow you to find the correct answer.</p> <p><u>Instructions to patient [and caregiver]:</u> For some patients, the low or "OFF" periods happen at certain times during day or when they do activities like eating or exercising. Over the past week, do you usually know when your low periods will occur? In other words, do your low periods <u>always</u> come at a certain time? Do they <u>mostly</u> come at a certain time? Do they <u>only sometimes</u> come at a certain time? Are your low periods totally unpredictable?"</p> <div style="margin-top: 20px;"> <div style="display: flex; justify-content: space-between; padding: 0 10px;"> <div style="width: 15%;">0: Normal:</div> <div>No motor fluctuations.</div> </div> <div style="margin-top: 10px;"> <div style="display: flex; justify-content: space-between; padding: 0 10px;"> <div style="width: 15%;">1: Slight:</div> <div>OFF times are predictable all or almost all of the time (&gt; 75%).</div> </div> <div style="margin-top: 10px;"> <div style="display: flex; justify-content: space-between; padding: 0 10px;"> <div style="width: 15%;">2: Mild:</div> <div>OFF times are predictable most of the time (51-75%).</div> </div> <div style="margin-top: 10px;"> <div style="display: flex; justify-content: space-between; padding: 0 10px;"> <div style="width: 15%;">3: Moderate:</div> <div>OFF times are predictable some of the time (26-50%).</div> </div> <div style="margin-top: 10px;"> <div style="display: flex; justify-content: space-between; padding: 0 10px;"> <div style="width: 15%;">4: Severe:</div> <div>OFF episodes are rarely predictable. (≤ 25%).</div> </div> </div> </div> </div> </div></div>	<div style="border: 1px solid black; width: 40px; height: 40px; margin: 0 auto;"></div>

# AG. UPDRS

## PART IV: MOTOR COMPLICATIONS

### C. "OFF" DYSTONIA

#### 4.6 PAINFUL OFF-STATE DYSTONIA

Instructions to examiner: For patients who have motor fluctuations, determine what proportion of the OFF episodes usually includes painful dystonia? You have already determined the number of hours of "OFF" time (4.3). Of these hours, determine how many are associated with dystonia and calculate the percentage. If there is no OFF time, mark 0.

Instructions to patient [and caregiver]: In one of the questions I asked earlier, you said you generally have \_\_\_\_ hours of low or "OFF" time when your Parkinson's disease is under poor control. During these low or "OFF" periods, do you usually have painful cramps or spasms? Out of the total \_\_\_\_ hrs of this low time, if you add up all the time in a day when these painful cramps come, how many hours would this make?

- 0: Normal: No dystonia OR NO OFF TIME.
- 1: Slight: < 25% of time in OFF state.
- 2: Mild: 26-50% of time in OFF state.
- 3: Moderate: 51-75% of time in OFF state.
- 4: Severe: > 75% of time in OFF state.

1. Total Hours Off: \_\_\_\_\_
2. Total Off Hours w/Dystonia: \_\_\_\_\_
3. % Off Dystonia =  $((2/1)*100)$ : \_\_\_\_\_





## AO. DYSRYS

### INTENSITY SCALE- IMPAIRMENT (PART 3)

0=No dyskinesia

1=Questionable or mild dyskinesia

2=Moderate dyskinesia with movements which are not intrusive nor distort voluntary movements

3=Severe dyskinesia which disturbs but does not prohibit posture or voluntary movements

4=Incapacitating dyskinesia which prohibits some postures and voluntary movements

IMPAIRMENT SCORE	Communication	Drinking	Dressing	Ambulation	Highest score
FACE					(16)
NECK					(17)
R ARM/SHOULDER					(18)
L ARM/SHOULDER					(19)
TRUNK					(20)
R LEG/HIP					(21)
L LEG/HIP					(22)

### DISABILITY SCALE (PART 4)

#### Communication

0=No dyskinesia

1=Dyskinesia present but does not impair communication

2=Dyskinesia impairs communication but patient is fully understandable

3=Dyskinesia interferes with communication such that parts of communication cannot be understood but overall content is understandable

4=Dyskinesia interferes with comprehension of overall communication

#### Drinking from a cup

0=No dyskinesia observed

1=Dyskinesia present but it does not affect performance of the task

2=Dyskinesia affect the smooth performance but causes no splashing or spilling

3=Dyskinesia affects performance such that patient spills a few drops of water

4=Dyskinesia affects performance such that patient spills more than a few drops or dyskinesia causes coughing or choking.

#### Dressing

0=No dyskinesia observed

1=Dyskinesia present but does not interfere with or slow dressing

2=Dyskinesia affects smooth performance of task but the performance is at most minimally slowed

3=Dyskinesia interferes and slows performance but it is completed within 60 seconds

4=Dyskinesia precludes completing the task within 60 seconds

#### Ambulation

0=No dyskinesia observed

1=Mild dyskinesia present but does not alter normal synchrony or cadence

2=Dyskinesia is present which alters the normal cadence of rising, sitting or walking but does not slow overall performance.

3=Dyskinesia is present which disrupts or distorts arising, sitting or walking. Performance is

slowed. Patient is able to rise and walk without imminent danger of falling.

4=Dyskinesia prohibits walking safely without assistance

Does the patient have dyskinesias?

Yes ☐<sub>1</sub> No ☐<sub>2</sub>

If yes, when did they start?

MM YYYY

PDD-26 given to patient?

Yes ☐<sub>1</sub> No ☐<sub>2</sub>

\_\_\_\_\_ (23)

\_\_\_\_\_ (24)

\_\_\_\_\_ (25)

\_\_\_\_\_ (26)

### Considering all of the activities above:

Patient exhibits: (check all applicable answers) \_\_\_\_\_ On dyskinesia \_\_\_\_\_ Off dystonia \_\_\_\_\_ Transition state (neither clearly On or Off) \_\_\_\_\_ No dyskinesia or dystonia

What movements were seen? (check all types) \_\_\_\_\_ chorea \_\_\_\_\_ dystonia \_\_\_\_\_ Other

The predominant dyskinesia was (check one) \_\_\_\_\_ chorea \_\_\_\_\_ dystonia \_\_\_\_\_ Other 37

## K. FREEZING OF GAIT QUESTIONNAIRE

This questionnaire should be completed by the researcher after asking and demonstrating the freezing phenomenon. All answers, except for item 3, should be based on the patient's experience in the last week.

<p>1. During your <u>worst</u> state – do you walk:</p> <p>0 Normally</p> <p>1 Almost normally – somewhat slow</p> <p>2 Slow but fully independent</p> <p>3 Need assistance or walking aid</p> <p>4 Unable to walk</p> <p>2. Are your gait difficulties affecting your daily activities and independence?</p> <p>0 Not at all</p> <p>1 Mildly</p> <p>2 Moderately</p> <p>3 Severely</p> <p>4 Unable to walk</p> <p>3. Do you feel that your feet get glued to the floor while walking, making a turn or when trying to initiate walking (freezing)?</p> <p>0 Never</p> <p>1 Very rarely – about once a month</p> <p>2 Rarely – about once a week</p> <p>3 Often – about once a day</p> <p>4 Always – whenever walking</p>	<p>4. How long is your <u>longest</u> freezing episode?</p> <p>0 Never happened</p> <p>1 1-2s</p> <p>2 3-10s</p> <p>3 11-30s</p> <p>4 Unable to walk for more than 30s</p> <p>5. How long is your <u>typical start hesitation</u> episode (freezing when initiating the first step)?</p> <p>0 None</p> <p>1 Takes longer than 1s to start walking</p> <p>2 Takes longer than 3s to start walking</p> <p>3 Takes longer than 10s to start walking</p> <p>4 Takes longer than 30s to start walking</p> <p>6. How long is your typical turning hesitation (freezing when turning)?</p> <p>0 None</p> <p>1 Resume turning in 1-2 s</p> <p>2 Resume turning in 3-10 s</p> <p>3 Resume turning in 11-30 s</p> <p>4 Unable to resume turning for more than 30 s</p>
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## AI. FACTORS SUGGESTING A DIAGNOSIS

Questions below are based on the **INVESTIGATOR's** opinion.

Which of the following features are present and therefore might have an impact on the correct diagnosis?

Answer 0 = No or 1 = Yes for each item.

- |  |                          |
|--|--------------------------|
| 1. Excessive stroke risk factors (e.g., diabetes, hypertension, cardiovascular disease) or past symptoms suggestive of cerebrovascular disease   | <input type="checkbox"/> |
| 2. Unusual or atypical risk factors, exposure, or past history (e.g., drug exposure, acute or chronic toxin exposure, acute infection preceding parkinsonism, repeated head trauma, boxer) | <input type="checkbox"/> |
| 3. Unusual or atypical presenting features or symptoms   | <input type="checkbox"/> |
| 4. Unusual or atypical course of disease:  | <input type="checkbox"/> |
| 4.1 Very rapid progression (to stage III in Hoehn and Yahr classification:<br>Some balance impairment, mild to moderate bilateral disease, physically independent)                         | <input type="checkbox"/> |
| 4.2 Static or little change  | <input type="checkbox"/> |
| 4.3 Hemiparkinsonism longer than 6 years   | <input type="checkbox"/> |
| 4.4 Onset before age 30  | <input type="checkbox"/> |
| 4.5 Other, specify: _____  |                          |

## AJ. SPECIFIC CLINICAL FEATURES

Answer 0 = No or 1 = Yes for each item.

1. Tremor:

1.1 Resting tremor present and typical for PD

☐

1.2 Resting tremor absent

☐

1.3 Prominent action tremor

☐

1.4 Other, specify: \_\_\_\_\_

2. Rigidity:

2.1 Rigidity is present and typical for PD

☐

2.2 Rigidity is absent

☐

2.3 Axial rigidity in excess of distal rigidity

☐

2.4 Marked unilateral or asymmetric rigidity

☐

2.5 Additional type of increased tone (i.e., paratonia, mitgehen, spasticity)

☐

2.6 Other, specify: \_\_\_\_\_

3. Akinesia/Bradykinesia:

3.1 Bradykinesia is present and typical for PD

☐

3.2 Bradykinesia is absent

☐

3.3 Pure Akinesia (without rigidity or tremor)

☐

3.4 Bradykinesia does not completely account for difficulty with rapid successive movements (e.g., apraxia, ataxia, pyramidal tract dysfunction)

☐

3.5 Other, specify: \_\_\_\_\_

4. Postural or gait disturbances:

4.1 Postural and gait disturbances are completely typical of PD

☐

4.2 Wide-based gait or ataxia

☐

4.3 Prominent freezing early in course

☐

4.4 Likely to fall if not extra careful

☐

4.5 Other, specify: \_\_\_\_\_

## AJ. SPECIFIC CLINICAL FEATURES (CONT)

5. Other hyperkinesias (not related to levodopa or agonists):
  - 5.1 Dystonia ☐
  - 5.2 Chorea ☐
  - 5.3 Myoclonus (include stimulus-induced) ☐
  - 5.4 Other (e.g., alien limbs): \_\_\_\_\_ ☐
6. Presence of body hemiatrophy ☐
7. Autonomic disturbances:
  - 7.1 Sexual dysfunction (significant change in past 1 year) ☐
  - 7.2 **FOR MALES ONLY:** Ask patient to rate his ability in the previous 3 months, without treatment, to have and maintain an erection adequate for intercourse (very poor=0, poor=1, fair=2, good=3, very good=4). ☐
  - 7.3 Urinary dysfunction (significant change in past 1 year) ☐
8. Oculomotor disturbances ☐
9. Eyelid disturbances (e.g., "apraxia" of lid opening, blepharospasm) ☐
10. Other neurological abnormalities atypical of parkinsonism (e.g., hyperreflexia, Babinski sign, sensory deficit, amyotrophy, limb apraxia, sleep apnea, dysmetria or Othercerebellar dysfunction) ☐
11. Little or no response to levodopa or a dopamine agonist (Enter N if never treated with dopaminergic medications) ☐
12. Presence of very rapid speech (tachyphemia) ☐
13. Presence of dysphagia or other bulbar dysfunction ☐
14. CT is suggestive of another cause of parkinsonism (Enter N if CT not done) ☐
15. If CT is showing any abnormalities, list them below: \_\_\_\_\_ ☐
16. MRI is suggestive of another cause of parkinsonism (Enter N if MRI not done) ☐
17. If MRI is showing any abnormalities, list them below: \_\_\_\_\_ ☐
18. DAT scan suggestive of Parkinsonism (Enter N if san not done). ☐
19. If there is anything unusual or atypical about this subject's disease (e.g., presentation, symptoms, signs, course, response to therapy, etc.) which could indicate an alternative diagnosis to Parkinson's disease (i.e., idiopathic parkinsonism with the presence of Lewy bodies in the substantia nigra), no matter how remote, please specify below: \_\_\_\_\_ ☐

## AK. LIKELIHOOD OF DIAGNOSIS

1. Based on all available information, in your opinion, what is the current probability that this individual has idiopathic Parkinson's disease (expressed in %)?
2. Meets current diagnostic criteria for probable PD as specified by the UK PDS Brain Bank? ☐  
(Bradykinesia with one of the following signs: muscular rigidity, rest tremor, postural instability)  
(0 = No, 1 = Yes)

3. Are you considering an alternative diagnosis to idiopathic PD in this patient? ☐<sub>1</sub> YES ☐<sub>2</sub> NO

- 3.1 If YES to above, which one of the following diagnoses is most likely (tick box/boxes as appropriate):

- PSP ☐<sub>1</sub>
- MSA ☐<sub>2</sub>
- DLB ☐<sub>3</sub>
- Dystonic tremor ☐<sub>4</sub>
- Vascular parkinsonism ☐<sub>5</sub>

Other (specify): \_\_\_\_\_

### 4. PD Dementia Scoring

- |   | YES                                   | NO                                    |
|---|---------------------------------------|---------------------------------------|
| 4.1 Idiopathic PD is the most likely diagnosis                    | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> |
| 4.2 Parkinson's disease developed at least 1 year before dementia | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> |
| 4.3 MMSE $\leq$ 26 or MOCA $\leq$ 20 (Nurse Q., page 4 and 6)     | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> |
| 4.4 IQCODE $>$ 57 (Informant Q., page 2)                          | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> |
| 4.5 Absence of delirium   | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> |
| 4.6 Absence of other abnormalities that obscure diagnosis         | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> |

**If answer to all of the above is YES then a diagnosis of dementia is probable.**

- |  | YES                                   | NO                                    |
|--|---------------------------------------|---------------------------------------|
| 5. Has this diagnosis been discussed with the patient? | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> |
| 6. Will this diagnosis be communicated to the GP?      | <input type="checkbox"/> <sub>1</sub> | <input type="checkbox"/> <sub>2</sub> |

7. What date was the letter sent to the GP about the probable dementia diagnosis?  
(administrator to fill in after letter is sent)

DD     MM     YYYY

## AS. DEMENTIA DIAGNOSIS

1. Patient has a diagnosis of dementia or probable dementia?

☐<sub>1</sub>  
YES

☐<sub>2</sub>  
NO

If yes, please enter details below:

2. Dementia Diagnosis:

PD Dementia

☐<sub>1</sub>  
YES

☐<sub>2</sub>  
NO

Alzheimer's Dementia

☐<sub>1</sub>  
YES

☐<sub>2</sub>  
NO

Vascular Dementia

☐<sub>1</sub>  
YES

☐<sub>2</sub>  
NO

Other (please specify, include mixed type):

\_\_\_\_\_

3. Dementia Diagnosis made by:

Independent dementia or memory clinic

☐<sub>1</sub>  
YES

☐<sub>2</sub>  
NO

Date \_\_\_\_\_

OPDC Discovery clinic

☐<sub>1</sub>  
YES

☐<sub>2</sub>  
NO

Date \_\_\_\_\_

Other clinic (please specify)

\_\_\_\_\_

Date \_\_\_\_\_

4. Additional cognitive tests:

Test (please specify)	Date	Score

## AL. PATIENT INTEREST IN OTHER INVESTIGATIONS

	YES	NO	N/A
1. Does the patient have any of the following: structural abnormalities on MRI or CT head (from CRF AI), claustrophobia, permanent pacemaker, aneurysm clips?	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	
1.1 If 'No' to question 1, then ask the following question: Would you like to be sent more information about undergoing a head MRI in our study? If 'Yes' to question 1.then mark 'Not applicable.'	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>
2. 'Would you like to be sent more information about undergoing a skin biopsy in our study?'	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>
3. 'Would you like to be sent more information about undergoing a lumbar puncture in our study?'	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	<input type="checkbox"/> <sub>3</sub>
5. Has the PIS2 form been given to subject?	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	
8. Smartphone tests completed in clinic?	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	
9. Participant given smartphone to take home?	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	
10. Participant sent link for app to use on own phone?	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	
11. Was an Axivity device given to the patient?	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	
12. Was a carer present?	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	
13. Was the NPI-D completed?	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	



## AL. PATIENT INTEREST IN OTHER INVESTIGATIONS (CONT.)

	YES	NO	N/A
15. Would you consider doing some additional memory tests at home on a tablet or computer?	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	
16. Would you consider attending an additional clinic visit to assess your memory in more detail?	<input type="checkbox"/> <sub>1</sub>	<input type="checkbox"/> <sub>2</sub>	

## AM. BLOOD SAMPLE RECORD

Seal purple-top tubes (DNA samples) in individual plastic bags per patient and then in a padded envelope



Send to address below:  
Regional Genetics Lab  
Old Road  
Churchill Hospital  
Headington  
Oxford, OX3 7LJ  
Mark: Samples Enclosed  
Send by internal post



Were DNA samples sent ?

Yes ☐

No ☐

Samples taken by:

---

Samples processed by:

---

**Spin yellow-top tubes** for 10 mins at 3700 RPM/13000g in a fixed angle centrifuge (eg. Hettich EBA 20 Portable Centrifuge) or at 3500 RPM/1300g in a Heraeus Labofuge 200 Centrifuge (non-portable)



**Aliquot** serum from 2 yellow-top tubes into 5 small tubes



Put small tubes in a bag and on dry ice or into a -80 deg C freezer



If using dry ice transport the samples to the JR the same day and log delivery on Sapphire



Were serum samples sent ?

Yes ☐

No ☐