PARKINSON'S DISEASE CARE

Audit Tool for Specialist Parkinson's disease/Movement Disorder Clinics

MARCH 1, 2022

University College Cork

This tool should be used for the purposes of reviewing healthcare records of people living with Parkinson's disease (PD) attending specialist PD clinics/services.

Before commencing data collection using this tool, please refer to the guidance document provided.

Does this patient have a current diagnosis of PD? ☐ Yes ☐ No → (*skip this chart*)

Please indicate the clinic code: ____

Date of chart review: ______/______/ 2022

Section 1: Demographic Information

1. Is this patient:

A new PD patient ☐ OR A returning patient ☐

2. Gender:

Male ☐ Female ☐ Non-binary ☐ Transgender ☐ Other ☐

3. Patient age:

Month of birth: Jan-Jun ☐ Jul-Dec ☐ Year of birth: ________________

4. Time since Parkinson's diagnosis:

Month of diagnosis: ______________ Year of diagnosis: ______________

5. Was the patient diagnosed with PD by this clinic/service?

Yes ☐ No ☐ → *(If 'no', skip to question 7)*

6. Please indicate the time (in months, to the nearest 0.25) between the date on the referral letter, and the date the patient was first seen at a clinic/service:

______________ Months

7. Please indicate the time (in months, to the nearest 0.25 month) between when the patient was last seen, and their second-to-last visit at this clinic/service:

______________ Months *OR* N/A (new patient) ☐

8. Is there evidence that the person received written information about PD, upon diagnosis?

Yes ☐ No ☐ Documented that patient was offered and declined ☐

9. Has the severity of the PD been recorded within the last 2 years?

Yes ☐ No ☐

→ If not, can you assess severity based on evidence in the notes (e.g., was already at stage 5 more than 2 years ago; or there is evidence for stage 3, etc.)?

If this is not possible, skip to Q10.

IF YES, please indicate the severity, and the tool used (where applicable):

i. Severity as worded ______________________________

ii. Tool used (e.g., Hoehn and Yahr): __________________________

iii. Score: _________________ *(record N/A if no tool used)*

10. Living Situation:

Lives alone ☐ Lives with spouse/partner ☐ Lives with other family ☐

Lives in long-term care ☐ Other (please specify): ___________________________________

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11. Ethnicity:

White Irish ☐ Irish Traveller ☐ White (any other background) ☐

Black Irish ☐ Black (any other background) ☐ Mixed ethnicity ☐

Asian Irish ☐ Asian (any other background) ☐ Not recorded ☐

Other (please specify): _______________________________

COMMENTS ON SECTION 1:

Section 2: Communication

COMMUNICATION WITH PATIENT

Please answer based on chart documentation for first 3 visits.

1. The patient received advice or direction in relation to driving.

Yes ☐ No ☐ N/A (doesn't drive) ☐ Documented that no issues with driving ☐

2. If working, the patient received advice or direction in relation to employment.

Yes ☐ No ☐ N/A (Patient is retired) ☐ N/A (Patient is not working) ☐

3. The patient received advice in relation to financial supports and entitlements (e.g., mortgage/income protection; specified/critical illness cover; social welfare benefits).

Yes ☐ No ☐ Patient offered but declined ☐

4. The patient received information about peer support available locally (e.g., Parkinson's Association branch/website)

Yes ☐ No ☐ Patient offered but declined ☐

5. Is there evidence of a care plan for this patient's PD?

Yes ☐ No ☐ → (If not, Skip to Q6)

Is there evidence that the plan was agreed upon with the patient and/or carer (where applicable)?

Yes ☐ No ☐

6. Is there evidence that a discussion has taken place regarding management of PD, apart from taking medications?

Yes ☐ No ☐ → (If not, Skip to Q7)

If YES, which of the following were discussed?

Goal setting	Yes ☐	No ☐
Self-monitoring of symptoms	Yes ☐	No ☐
Managing mood	Yes ☐	No ☐
Physical activity	Yes ☐	No ☐
Referral to educational programme	Yes ☐	No ☐
Optimising sleep	Yes ☐	No ☐

Other (please specify)

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7. The patient was given a phone number for a point of contact linked to this clinic/service? (e.g., PD nurse specialist)

Yes ☐ No ☐

If YES, please specify their role/discipline): ______________________________

COMMUNICATION WITH CARE PARTNER

8. Does this patient have a care partner?

Yes ☐ No ☐ → (If not, skip to Section 3)

9. A discussion has taken place about the availability of supports locally (e.g., peer support groups, respite services, etc.) for the care partner?

Yes ☐ No ☐ → (Skip to Q10) N/A (Info declined) ☐ → (Skip to Q10)

If yes, which of the following supports were discussed?

Respite ☐ Day Services ☐ Peer support ☐

Unclear which supports were discussed ☐ Other (please specify): ☐

____

10. The carer received advice regarding financial support/entitlements (e.g., carer's allowance; carer's support grant).

Yes ☐ No ☐ N/A (Carer declined) ☐

COMMENTS ON SECTION 2:

Section 3: Symptom Assessment

Note: Please review the patient's 3 most recent visits at the clinic when answering this section.

1. The patients' blood pressure (BP) was recorded?

Yes ☐ No BP recorded ☐ N/A (for specified reason[s]) ☐ → (Skip to Q2)

If BP was recorded, please indicate recorded details:

Lying, then standing ☐ Sitting, then standing ☐

Sitting only ☐ Not specified but only one reading ☐

Not specified but two readings ☐

Other (Please specify) or comment: ______________________________

2. An assessment of cognition was conducted.

No, but known cognitive impairment as per clinic letter ☐

Yes – using a formal tool ☐

Yes – informal assessment recorded ☐ → (Skip to Q3)

No assessment recorded ☐ → (Skip to Q3)

If a formal cognitive assessment was used, please indicate i) the tool and ii) the patient's score:

Tool: ____________________________ Score: ____________________________

Is there evidence that a cholinesterase inhibitor was considered after this cognitive test?

Yes ☐ No ☐ Comment______________________________

3. An assessment of functional ability (ADLs or IADLs) was conducted by a healthcare professional?

Yes (formal tool) ☐ Yes (informal assessment) ☐ No assessment recorded ☐

4. The patient was asked about the presence of pain?

No ☐ → (Skip to Q5)

Yes (but no pain present) ☐ → (Skip to Q5)

Yes (patient reported pain) ☐

Was pain severity assessed?

Yes (formal tool) ☐ Yes (informal assessment) ☐ No assessment recorded ☐

5. Was an assessment of nutritional status conducted? *Tick 'best' answer (see guidance document)*

No assessment of nutritional status recorded ☐ → (Skip to Q6)

Yes – using the MUST or MNA tool etc. ☐

Yes - BMI recorded ☐

Yes - weight only recorded ☐

Yes – evidence of informal assessment only ☐

Based on this, was the patient determined to be at risk for or currently malnourished, OR had low BMI OR evidence of weight loss?

None of these ☐ → (Skip to Q6)

Yes ☐ → answer the three questions below:

Was the patient (and/or carer) asked about the following:

Anorexia/appetite Yes ☐ No ☐

Nausea/vomiting Yes ☐ No ☐

Swallowing difficulties Yes ☐ No ☐

Was the patient referred to a dietician?

Yes ☐ No ☐

6. Was the patient and/or carer asked about falls?

Yes (fall(s) reported) ☐ Yes (no falls to date) ☐ → (Skip to Q7)

This is not recorded ☐ → (Skip to Q7)

Was a falls risk factor assessment conducted by a healthcare professional (looking for risks for falls e.g., vision impairment, poor balance)?

Yes – using a formal tool (e.g. QUICK SCREEN/FRAT) ☐ Yes – informal assessment ☐

No assessment of risk factors recorded ☐

7. Was an assessment of bone density arranged?

Yes ☐ No ☐ N/A (already known osteopenia/osteoporosis) ☐

N/A for other specified reason(s) ☐ ______________________

8. Was an assessment of mobility conducted by a healthcare professional?

Yes (formal tool) ☐ Yes (informal assessment) ☐ No assessment recorded ☐

9. Was an assessment of gait conducted by a healthcare professional?

Yes ☐ No ☐

10. Was the patient asked about bladder function?

Yes ☐ No ☐

11. Was the patient asked about constipation?

Yes ☐ No ☐

12. Was the patient asked about any of the following motor symptoms?

A. **FREEZING**

Yes – it's a problem ☐ Yes (but not a problem) ☐ No evidence of inquiry ☐

B. **DYSKINESIA**

Yes – it's a problem ☐ Yes (but not a problem) ☐ No evidence of inquiry ☐

C. **'WEARING OFF'**

Yes – it's a problem ☐ Yes (but not a problem) ☐ No evidence of inquiry ☐

D. **BRADYKINESIA**

Yes – it's a problem ☐ Yes (but not a problem) ☐ No evidence of inquiry ☐

E. **TREMOR**

Yes – it's a problem ☐ Yes (but not a problem) ☐ No evidence of inquiry ☐

F. **RIGIDITY**

Yes – it's a problem ☐ Yes (but not a problem) ☐ No evidence of inquiry ☐

G. **DYSTONIA**

Yes – it's a problem ☐ Yes (but not a problem) ☐ No evidence of inquiry ☐

13. Was the patient and/or carer asked about communication difficulties?

No ☐ Yes ☐

If communication difficulties were present, was the person referred to an SLT?

Yes ☐ No ☐ N/A (no issue) ☐

14. Was the patient and/or carer asked about difficulties with their swallow?

Yes ☐ No ☐ N/A (no issue) ☐

If swallow difficulties were present, was the person referred to an SLT?

Yes ☐ No ☐ N/A (no issue) ☐

15. Was the patient and/or carer asked about problems with drooling?

Yes ☐ No ☐

16. Was the patient and/or carer asked about the presence of fatigue (NB: not sleepiness)?

Yes ☐ No ☐

17. Was the patient and/or carer asked about any sleep-related problems?

Yes (patient has sleep problems) ☐

Yes (no sleep problems reported) ☐ -→ (Skip to Q18)

No ☐ (IF no, skip to Q18)

If the patient has reported sleep problems, were they asked about the following:

Clarification re. sleep latency issues versus problems staying asleep	Yes ☐	No ☐
REM sleep behaviour disorder	Yes ☐	No ☐
Sleep Apnea	Yes ☐	No ☐
Restless leg syndrome	Yes ☐	No ☐
Nocturnal akinesia/stiffness	Yes ☐	No ☐
Night sweats	Yes ☐	No ☐
Daytime sleepiness	Yes ☐	No ☐

Comments____

18. If the patient has a life partner, were they asked about sexual dysfunction?

Yes ☐ No ☐ N/A (e.g., patient is single, part of a religious order) ☐

19. The patient and/or carer was asked about problems with mood and/or anxiety?

Yes (no problems) ☐ Yes (patient has problems) ☐

No ☐ N/A (no issue) ☐

If the patient has problems with mood/anxiety, were they asked about:

A) Severity/persistence Yes ☐ No ☐
B) Suicidal ideation: Yes ☐ No ☐
C) Suicidal intent: Yes ☐ No ☐

Was antidepressant medication commenced? ***Yes*** ☐ ***No*** ☐

If the patient presents an immediate risk to themselves/others, were they referred for specialist mental health input?

Yes ☐ No ☐ N/A (not a risk to themselves or others) ☐

COMMENTS ON SECTION 3:

Section 4: Pharmacological management

Note: 'PD medications', in this context, include: Levodopa; Duodopa pump; Stalevo; Dopamine Agonists by any route; MAO-B Inhibitors; Amantadine (Symmetrel); Anticholinergics; Antipsychotics.

1. Is this patient currently taking any of the above medications?

Yes ☐

No ☐ → (Skip to Section 5)

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2. A current list of the patient's PD medications is documented.

Yes ☐ No ☐

3. Is an indication documented for each new prescription in the last 3 visits?

Yes ☐ No ☐

Was the patient asked in the last 3 visits about issues with:

Medication adherence: Yes ☐ No ☐ N/A (new patient) ☐
The need for medication-taking supports: Yes ☐ No ☐ N/A (new patient) ☐

LEVODOPA/STALAEVO/ANY DOPAMINE AGONIST

4. Is this patient currently taking LEVODOPA/STALAEVO/ANY DOPAMINE AGONIST?

Yes ☐ No ☐ → (Skip to Q8 below)

Which one was commenced most recently: Med: ____________Year: _______

NB: Please answer the following for that medication only:

5. When this medication was first prescribed, is there evidence that the following were discussed?

N/A, commenced elsewhere ☐ → skip to Q6

Potential benefits Yes ☐ No ☐

Potential risks/side effects Yes ☐ No ☐

6. At the return visit after commencing this medication, the clinician enquired about:

N/A (only commenced at last visit) ☐ → skip to Q7

Benefit/effectiveness	Yes ☐	No ☐
Any side effects	Yes ☐	No ☐
Dyskinesias	Yes ☐	No ☐
Daytime drowsiness	Yes ☐	No ☐
Sudden drowsiness/sleep attacks	Yes ☐	No ☐
Impulse control disorders	Yes ☐	No ☐
Confusion	Yes ☐	No ☐
Visual hallucinations	Yes ☐	No ☐

7. Where impulse control problems are identified (whether through direct questioning or patient/family report), the following has occurred:

N/A ☐ *(NB: Tick and Skip to Q8, if N/A)*

Collateral history of current symptoms: Yes ☐ No ☐ N/A(no carer present) ☐

Collateral history of premorbid impulsivity: Yes ☐ No ☐ N/A(no carer present) ☐

A discussion regarding impact on quality of life: Yes ☐ No ☐

A discussion on possible treatments (e.g., reducing/stopping DA): Yes ☐ No ☐

The patient's dopamine agonist dosage was modified: Yes ☐ No ☐

Symptoms monitored at follow-up: Yes ☐ No ☐ N/A (final visit prior to audit) ☐

8. Where possible psychotic symptoms are identified, the following has occurred:

N/A ☐ *(NB: Tick and Skip to Q9, if N/A)*

An assessment to determine the trigger(s): Yes ☐ No ☐
A discussion of impact of the symptoms on quality of life: Yes ☐ No ☐
Treatment was offered: Yes ☐ No ☐

Detail (e.g. meds or other):

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Monoamine Oxidase Type B (MAO-B) Inhibitors

9. Is this patient currently taking an MAO-B inhibitor?

Yes ☐ No ☐ → (Skip to Q12)

10. When the MAO-B inhibitor was first prescribed, is there evidence that the following were discussed?

N/A, commenced elsewhere ☐ → skip to Q12
Potential benefits: Yes ☐ No ☐
Potential risks/side effects: Yes ☐ No ☐

11. At the return visit after commencing this, the clinician enquired about:

N/A, only commenced at last clinic visit ☐ → Skip to Q12
Benefits/ Effectiveness Yes ☐ No ☐
Any side effects Yes ☐ No ☐

SYMMETREL (AMANTADINE)

12. Is this patient currently taking SYMMETREL?

Yes ☐ No ☐ → (Skip to Q15)

13. When SYMMETREL was first prescribed, is there evidence that the following were discussed?

N/A, commenced elsewhere ☐ → (Skip to Q15)

Potential benefits: Yes ☐ No ☐
Potential risks/side effects: Yes ☐ No ☐

14. At the return visit after commencing this, the clinician enquired about:

N/A, only commenced at last clinic visit ☐ → (Skip to Q15)

Benefit/ Effectiveness Yes ☐ No ☐
Any side effects Yes ☐ No ☐
Confusion Yes ☐ No ☐

ANTICHOLINERGICS

15. Is this patient currently taking an ANTICHOLINERGIC medication?

Yes ☐ No ☐ → (Skip to Q18)

16. When the ANTICHOLINERGIC was first prescribed, is there evidence that the following were discussed?

N/A, commenced elsewhere ☐ → (Skip to Q18)

Potential benefits: Yes ☐ No ☐
Potential risks/side effects (e.g., dry mouth, constipation, confusion): Yes ☐ No ☐

17. At the return visit after commencing this, the clinician enquired about:

N/A, only commenced at last clinic visit ☐ → (Skip to Q18)

Benefits/Effectiveness Yes ☐ No ☐
Any side effects Yes ☐ No ☐
Confusion/language issues: Yes ☐ No ☐
Sedation: Yes ☐ No ☐
Constipation: Yes ☐ No ☐
Dry Mouth: Yes ☐ No ☐

ANTIPSYCHOTICS

18. Is this patient currently taking an ANTIPSYCHOTIC medication?

Yes ☐ No ☐ → (Skip to Section 5)

19. When the ANTIPSYCHOTIC was first prescribed, is there evidence that the following happened?

N/A, commenced elsewhere ☐ → (Skip to Section 5)

Assessment of impact of psychosis on quality of life Yes ☐ No ☐
Assessment of risk of harm from psychosis Yes ☐ No ☐
Discussion of potential benefits: Yes ☐ No ☐
Discussion of Potential risks/side effects: Yes ☐ No ☐

20. At the return visit after commencing this, the clinician enquired about:

N/A, only commenced at last clinic visit ☐ → (Skip to Section 5)

Benefit or effectiveness Yes ☐ No ☐
Any side effects Yes ☐ No ☐
Motor side effects specifically Yes ☐ No ☐
Confusion: Yes ☐ No ☐
Sedation: Yes ☐ No ☐

COMMENTS ON SECTION 4:

Section 5: Multidisciplinary Input

1. Has the person been seen by a PD nurse specialist?

Yes ☐ No ☐

Is a PD nurse specialist available to patients at this clinic? Yes ☐ No ☐

2. Is there evidence of physiotherapy involvement in the care of this person?

Yes ☐ No ☐ N/A – no involvement needed for recorded reasons ☐

3. Is there evidence of occupational therapy involvement in the care of this person?

Yes ☐ No ☐ N/A – no involvement needed for recorded reasons ☐

4. Is there evidence of SLT involvement in the care of this person?

Yes ☐ No ☐ N/A – no involvement needed for recorded reasons ☐

5. Is there evidence of dietician involvement in the care of this person?

Yes ☐ No ☐ N/A – no involvement needed for recorded reasons ☐

6. Is there evidence of social work involvement in the care of this person?

Yes ☐ No ☐ N/A – no involvement needed for recorded reasons ☐

7. Is there evidence of neuro/clinical psychology involvement in the care of this person?

Yes ☐ No ☐ N/A – no involvement needed for recorded reasons ☐

COMMENTS ON SECTION 5:

Section 6: Device-Assisted Therapies

NB: This section only applies to patients with 'complex' PD (otherwise please skip section 7).

'Complex' PD applies to patients who were diagnosed 4+ years ago; AND are taking 4+ doses of dopaminergic agents per day; AND present with troublesome 'wearing off', dyskinesia or other motor fluctuations, or with non-motor fluctuations, despite optimisation of medical therapy.

1. Does this patient have 'complex' PD as defined above?

Yes ☐

No ☐ → (Skip to Section 7)

2. Was an assessment of their suitability for Deep Brain Stimulation (DBS) conducted?

Yes ☐ No ☐ No, documented reason why not suitable ☐

3. Were they offered continuous subcutaneous apomorphine infusion?

Yes ☐ No ☐ No, documented reason why not suitable ☐

Details: ____

4. Were they offered a duodopa pump (intestinal gel)?

Yes ☐ No ☐ No, documented reason why not suitable ☐

IF Yes, Please indicate date of the appointment for trial (dd/mm/yy): ____/____/____

COMMENTS ON SECTION 6:

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Section 7: Advance Care Planning

1. Has a discussion taken place between the clinician, the patient, and their family/care partner (where applicable), regarding advance care planning?

Yes ☐

No discussion recorded ☐ → Skip this section

N/A – for recorded reasons ________________ ☐ → Skip this section

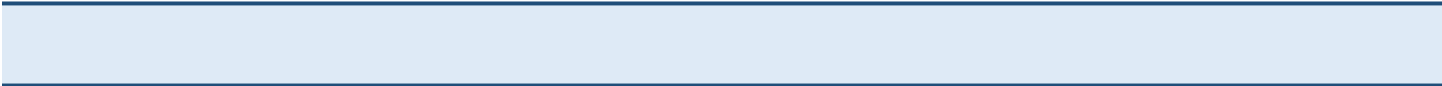
If such a discussion has taken place, which of the following were discussed:

Enduring power of attorney	Yes ☐ No ☐
Surrogate decision maker	Yes ☐ No ☐
Advanced PD care needs (e.g., feeding tube)	Yes ☐ No ☐
Resuscitation decision	Yes ☐ No ☐
Preferred place of death	Yes ☐ No ☐

2. Has a separate discussion taken place with family/carers (where applicable) regarding their palliative support needs?

Yes ☐ No ☐ N/A (no family/carer) ☐ N/A (for recorded reasons) ☐

COMMENTS ON SECTION 7:



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