

Exercise Appendix
HTA: Policies and Principles
Week 6: Outcomes II

Table of Contents

Parkinson's Disease Questionnaire-39	2
PDQ-39 Scoring	7
EQ-5D-3L	10
ICECAP-O	13

Parkinson's Disease Questionnaire-39

2

Parkinson's Disease Quality of Life Questionnaire (PDQ-39)

Due to having Parkinson's disease,
how often during the last month have you...

Please **tick one box** for each question

	Never	Occasionally	Sometimes	Often	Always or cannot do at all
1. Had difficulty doing the leisure activities which you would like to do?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Had difficulty looking after your home, e.g. DIY, housework, cooking?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Had difficulty carrying bags of shopping?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Had problems walking half a mile?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Had problems walking 100 yards?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Had problems getting around the house as easily as you would like?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Had difficulty getting around in public?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Needed someone else to accompany you when you went out?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please check that you have **ticked one box for each question** before going onto the next page.

Due to having Parkinson's disease,
how often during the last month have you...

Please **tick one box** for each question

	Never	Occasionally	Sometimes	Often	Always or cannot do at all
9. Felt frightened or worried about falling over in public?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Been confined to the house more than you would like?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Had difficulty washing yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Had difficulty dressing yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Had problems doing up buttons or shoe laces?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Had problems writing clearly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Had difficulty cutting up your food?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Had difficulty holding a drink without spilling it?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Felt depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Felt isolated and lonely?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please check that you have **ticked one box for each question**
before going onto the next page.

Due to having Parkinson's disease,
how often during the last month have you...

Please **tick one box** for each question

	Never	Occasionally	Sometimes	Often	Always
19. Felt weepy or tearful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Felt angry or bitter?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Felt anxious?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Felt worried about your future?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Felt you had to conceal your Parkinson's from people?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Avoided situations which involve eating or drinking in public?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Felt embarrassed in public due to having Parkinson's disease?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Felt worried by other people's reaction to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Had problems with your close personal relationships?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please check that you have **ticked one box for each question**
before going onto the next page.

Due to having Parkinson's disease,
how often during the last month have you...

Please **tick one box** for each question

	Never	Occasionally	Sometimes	Often	Always
28. Lacked support in the ways you need from your spouse or partner? <i>If you do not have a spouse or partner, please tick here</i> <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Lacked support in the ways you need from your family or close friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Unexpectedly fallen asleep during the day?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Had problems with your concentration, e.g. when reading or watching TV?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Felt your memory was bad?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Had distressing dreams or hallucinations?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Had difficulty with your speech?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. Felt unable to communicate with people properly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please check that you have **ticked one box for each question**
before going onto the next page.

Due to having Parkinson's disease,
how often during the last month have you...

Please tick one box for each question

	Never	Occasionally	Sometimes	Often	Always
36. Felt ignored by people?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. Had painful muscle cramps or spasms?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. Had aches and pains in your joints or body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. Felt unpleasantly hot or cold?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please check that you have ticked one box for each question.

Thank you for completing the questionnaire.

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<http://innovation.ox.ac.uk/outcome-measures/parkinsons-disease-questionnaire-pdq-39-pdq-8/>

Coding for the PDQ-39 & PDQ-8

PDQ-39

Coding system for questions

All questions on the PDQ-39 are coded in the same way.

We recommend that data is entered using the following codes:

- 0 = Never
- 1 = Occasionally
- 2 = Sometimes
- 3 = Often
- 4 = Always (or cannot do at all, if applicable)

Dimensions and their questions

Mobility	10 questions, nos. 1 to 10
Activities of daily living (ADL)	6 questions, nos. 11 to 16
Emotional well being	6 questions, nos. 17 to 22
Stigma	4 questions, nos. 23 to 26
Social support	3 questions, nos. 27 to 29
Cognitive impairment (Cognitions)	4 questions, nos. 30 to 33
Communication	3 questions, nos. 34 to 36
Bodily discomfort	3 questions, nos. 37 to 39

Scoring for each dimension

Each dimension is calculated as a scale from 0 to 100

0 = no problem at all; 100 = maximum level of problem

If the response to a question is missing, no scale score is calculated for that individual for that dimension. This will preclude calculation of the PDQ-39 single index score from the eight domain scores although it may still be possible to calculate the PDQ-8 single index score (see below).

Formula for scoring each dimension

$$\frac{\text{sum of scores of each question in dimension}}{4 (\text{max. score per question}) \times \text{nos. questions in dimension}} \times 100$$

Mobility = (scores of questions 1+2+3+4+5+6+7+8+9+10) / (4 x 10) x 100

Activities of daily living = (scores of questions 11+12+13+14+15+16) / (4 x 6) x 100

Emotional well being = (scores of questions 17+18+19+20+21+22) / (4 x 6) x 100

Stigma = (scores of questions 23+24+25+26) / (4 x 4) x 100

Social support = (scores of questions 27+28+29) / (4 x 3) x 100

note: if respondents indicate that they do not have a spouse or partner on question 28 then social support can be calculated as follows:

Social support = (scores of questions 27+29) / (4 x 2) x 100

Cognitions = (scores of questions 30+31+32+33) / (4 x 4) x 100

Communication = (scores of questions 34+35+36) / (4 x 3) x 100

Bodily discomfort = (scores of questions 37+38+39) / (4 x 3) x 100

Scoring for single index (PDQ-39-SI)

Single index = Sum of dimension scores / 8

PDQ-8

Coding system for questions

All questions on the PDQ-8 are coded in the same way.

We recommend that data is entered using the following codes:

- 0 = Never
- 1 = Occasionally
- 2 = Sometimes
- 3 = Often
- 4 = Always

Single index (PDQ-8-SI)

Formula for the PDQ-8 Single Index

$$\frac{\text{sum of scores of each question}}{4 \text{ (max. score per question)} \times 8 \text{ (total number of questions)}} \times 100$$

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EQ-5D-3L



Health Questionnaire

English version for the UK

(Validated for Ireland)

Under each heading, please tick the ONE box that best describes your health TODAY.

MOBILITY

- I have no problems in walking about ☐
- I have some problems in walking about ☐
- I am confined to bed ☐

SELF-CARE

- I have no problems with self-care ☐
- I have some problems washing or dressing myself ☐
- I am unable to wash or dress myself ☐

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

- I have no problems with performing my usual activities ☐
- I have some problems with performing my usual activities ☐
- I am unable to perform my usual activities ☐

PAIN / DISCOMFORT

- I have no pain or discomfort ☐
- I have moderate pain or discomfort ☐
- I have extreme pain or discomfort ☐

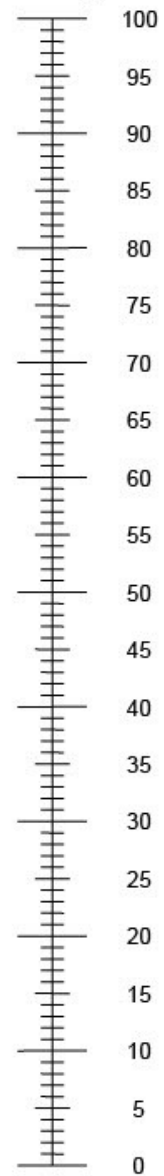
ANXIETY / DEPRESSION

- I am not anxious or depressed ☐
- I am moderately anxious or depressed ☐
- I am extremely anxious or depressed ☐

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
0 means the worst health you can imagine.
- Please mark an X on the scale to indicate how your health is TODAY.
- Now, write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =

The best health
you can imagine



The worst health
you can imagine

ABOUT YOUR QUALITY OF LIFE

By placing a tick (✓) in ONE box in EACH group below, please indicate which statement best describes your quality of life at the moment.

1. Love and Friendship

- I can have all of the love and friendship that I want
- I can have a lot of the love and friendship that I want
- I can have a little of the love and friendship that I want
- I cannot have any of the love and friendship that I want

	4
	3
	2
	1

2. Thinking about the future

- I can think about the future without any concern
- I can think about the future with only a little concern
- I can only think about the future with some concern
- I can only think about the future with a lot of concern

	4
	3
	2
	1

3. Doing things that make you feel valued

- I am able to do all of the things that make me feel valued
- I am able to do many of the things that make me feel valued
- I am able to do a few of the things that make me feel valued
- I am unable to do any of the things that make me feel valued

	4
	3
	2
	1

4. Enjoyment and pleasure

- I can have all of the enjoyment and pleasure that I want
- I can have a lot of the enjoyment and pleasure that I want
- I can have a little of the enjoyment and pleasure that I want
- I cannot have any of the enjoyment and pleasure that I want

	4
	3
	2
	1

5. Independence

- I am able to be completely independent
- I am able to be independent in many things
- I am able to be independent in a few things
- I am unable to be at all independent

	4
	3
	2
	1

Tick
one
box
only in
each
section