

# Cognitive Interviewing to Develop a New Health-Related Quality of Life Measure for Parkinson's Disease: The Preference-Based Parkinson's Disease Index (PB-PDI)

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## Abstract

Preference-based measures (PBM) for health-related quality of life (HRQoL) are essential in assessing the cost-utility of different treatment options. The preference-based Parkinson's disease Index (PB-PDI) is being developed for people with Parkinson's disease (PD). The aim of this study was to refine the PB-PDI through cognitive interviews with people with PD. Cognitive debriefing was conducted to assess patients' interpretation of items, both in English and French. Participants' feedback guided the iterative modification of the PB-PDI and items were accepted for final inclusion if they were endorsed by three consecutive participants. A total of 16 participants provided feedback on the items, refined the response options, and discussed how to clarify questions. They selected a 2-week timeframe for the PB-PDI recall period. At the end of the cognitive interviews, all seven items and their response options were endorsed in both languages. The cognitive interview process allowed us to refine items and ensure that they were clear in terms of instructions and response options from the perspective of people with PD. The next step will be to elicit preference weights to develop a scoring algorithm and assess its measurement properties.

## Keywords

Parkinson's disease, Health-related quality of life, Patient-reported outcome measures, Cognitive interviews

## Key Points

- The wording of the seven items of PB-PDI (sleep, memory, walking, fatigue, mood, tremor, and dexterity) was endorsed by 16 people with PD.
- A two-week timeframe was endorsed as optimal for the recall period.
- Response options for each of the seven items demonstrated interval properties (linearly increasing VAS values across levels of response options).
- The PB-PDI will provide a single index of HRQoL, which is fit for the purpose of relating costs to outcomes.

tremors, rigidity, and bradykinesia (ie, slow movement).<sup>4,5</sup> People with PD also commonly experience non-motor

## Introduction

Parkinson's disease (PD) is the second most common neurodegenerative disease that is accompanied by motor and non-motor symptoms.<sup>1-3</sup> Major motor symptoms of PD include

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symptoms such as fatigue, cognitive changes, sleep disturbances, and depression. These symptoms can gradually worsen over time and impact daily life and psychological functioning, which can have a substantial impact on one's health-related quality of life (HRQoL).<sup>2,3,6</sup>

Evaluating HRQoL is important in incorporating the patient's view when evaluating the impairments and activities affected by disease and its treatment.<sup>7-9</sup> The consistent use of HRQoL measures can effectively work toward voicing a patient's health concerns, identifying a decline in health, and aiding in overall health management.<sup>9,10</sup> A key feature of HRQoL measures is that they are patient-reported outcomes (PROs). A PRO is a health outcome that is directly reported by the patient without interpretation of the patient's response by a healthcare provider or anyone else.<sup>11,12</sup> Many different instruments have been developed to measure HRQoL; however, in general, these measures fall into two categories based on how they are composed and scored: (1) health profiles and (2) preference-based measures (PBMs).

Health profiles are scored by sub-scale, where each sub-scale characterizes a domain of HRQoL, such as the Short Form-36 (SF-36) Health Survey,<sup>13</sup> the Scales for Outcomes in Parkinson's disease (SCOPA),<sup>14</sup> and Non-Motor Symptoms Scale for Parkinson's Disease (NMSS).<sup>15</sup> The assessment of HRQoL can also be carried out through the administration of PBMs. PBMs have a weight attached to each domain, and produce a single index score that considers improvements in one area against declines in another. Existing preference-based measures used in PD are generic, such as the EuroQol-5D (EQ-5D). Although generic measures are beneficial when comparing different health conditions,<sup>16</sup> previous research has shown that these measures are missing domains important to people with PD and may not thoroughly assess their health concerns.<sup>17,18</sup>

Thus, our research group recently developed a new PRO instrument for PD: the preference-based PD Index (PB-PDI), including patient-defined seven domains that are important to the quality of life of people with PD (sleep, fatigue, tremor, mood, walking, memory, and dexterity). The aim of this current study was to perform cognitive interviews with people living with PD to review and refine the seven items and develop the final version of PB-PDI in English and French. Through cognitive interviews of people with PD, we captured their perspectives on whether (1) the items in the PB-PDI were clear and easy to understand; (2) the response choices of each item were appropriate; and (3) the recall time period was relevant.

## Methods

### Study Design

This was a cross-sectional study. Qualitative semi-structured cognitive debriefing interviews were conducted to assess patients' interpretation of items.

### Participants

Participants were recruited for over an 8-month period through the Quebec Parkinson Network (QPN). Individuals diagnosed with PD were invited to participate in the study if they were 18 years and older and could speak and understand English and/or French. People with PD who had a major comorbid condition (eg, severe dementia, severe psychiatric, neurological, or other medical conditions) were excluded from this study.

### Procedure

Figure 1 provides an overview of the stages that were involved in the development of the PB-PDI. This paper focuses on Stage 4 which involved cognitive interviews with people with PD. In this stage, the research team finalized the wording of the seven items in English and French, selected an appropriate recall time, and assessed the distance between response choice levels.

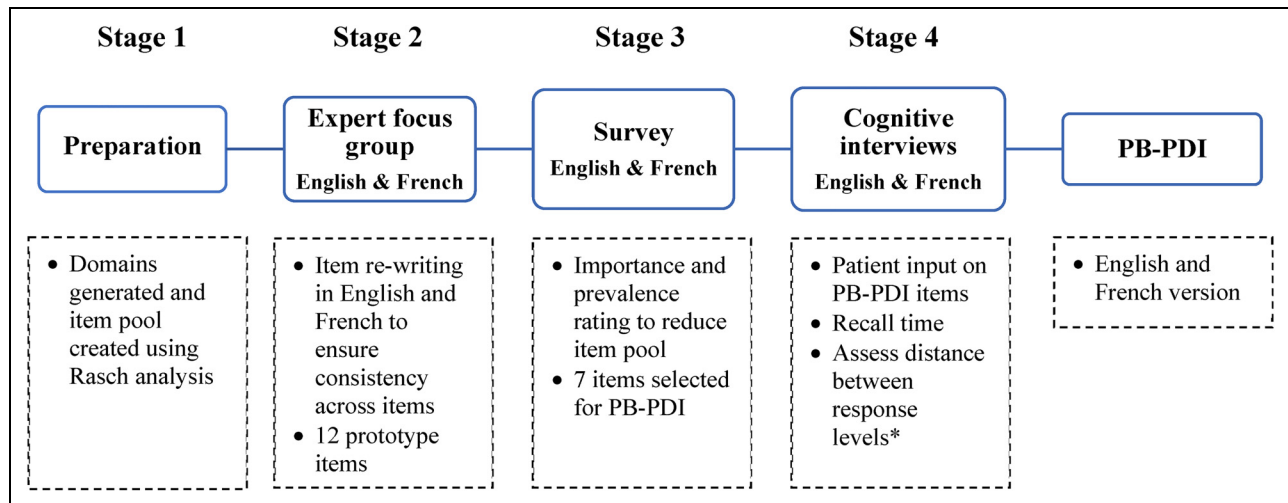
### Data Collection

Participants selected an interview session time through e-mail. They had the choice of participating in a video call (eg, Zoom) or a phone interview depending on their preferences. Participants were asked to complete the prototype PB-PDI before the cognitive interview. Afterwards, following a structured interview guide,<sup>19</sup> each participant engaged in cognitive debriefing of four to six items. Four to six items were selected to minimize participant burden. The interview took approximately 45 to 60 min to complete. Following comments from the participants, the prototype PB-PDI was iteratively modified before an interview with the next participant. During the interviews, verbal probing and the think-aloud method were applied to encourage participants to answer questions regarding the meaning of the items, clarity, and recall time period. An item was accepted for inclusion in the final version of PB-PDI if it was endorsed by three participants in a row. After all items in English were endorsed and finalized, cognitive interviews in French were also conducted. The same process was applied to the interviews in French.

During the interviews, participants were also presented with a Visual Analogue Scale (VAS) to assess the interval properties of the response options of each item in the PB-PDI. For each item, a participant was provided with a VAS with the first response option placed as an anchor at the left of the line (representing a value of 0) and the fourth response option at the right end of the line (representing a value of 10). The participant's task was to indicate where the second and third response levels would fall in this scale.<sup>8</sup>

### Data Analysis

Descriptive statistics were calculated to describe the sample population involved in cognitive debriefing interviews and



**Figure 1.** Development of items for the PB-PDI in English and French. \* The selected items in Stage 3 had 3-response levels; however, the research team noted that a 3-level version may be prone to ceiling effects, especially in high-functioning groups and thus may not be sensitive enough to small changes in health. Response levels expanded to 4-levels during cognitive interviews in stage 4.

the VAS scale response ratings using Microsoft Excel. Conducting and transcribing interviews proceeded concurrently so that preliminary analysis guided subsequent data collection.<sup>20</sup> Throughout the cognitive debriefing interview process, the feedback from the previous interview was assessed and reviewed before the next interview. This was to ensure the meaning of items was preserved, problems regarding consistency and/or comprehensibility of response options resolved, and any revisions were taken to the next interview for testing.

## Results

### Participant Characteristics

A total of 16 people with PD participated in the cognitive interviews. A description of the characteristics of the sample is summarized in Table 1.

### Findings from Cognitive Debriefing Interviews

**Item Clarity.** Item revisions based on English and French cognitive debriefing interviews from 16 participants are described in Table 2. A total of 11 out of 16 participants provided feedback on the English version of the PB-PDI items. After the English interviews, a group of language experts in our research team refined the wording of the French version of the index to match the English one. Feedback on the French version was received from 5 bilingual participants. Regarding item endorsement, “X” represents not satisfied and “✓” represents satisfied in Table 2.

At the end of the cognitive interviews, all seven items (ie, sleep, memory, walking, fatigue, mood, tremor, dexterity) were endorsed. The following section elaborates on the details of each item discussed during the English and

**Table 1.** Sociodemographic Characteristics of Participants.

Characteristics	Participants (n = 16)
Sex, n (%)	
Female	8 (50.0)
Age (years), mean (SD)	60.8 (10.5)
Duration of PD (years), mean (SD)	10.8 (5.3)
Interview language, n (%)	
English	11 (68.7)
French	5 (31.3)
Geographic location, n (%)	
Province of Quebec	16 (100.0)
Education level, n (%)	
CEGEP or College	4 (25.0)
Bachelor’s degree	4 (25.0)
Graduate degree	8 (50.0)
Household annual income, n (%)	
Less than \$49,999	3 (18.7)
\$50,000–\$99,999	4 (25.0)
\$100,000–\$149,999	5 (31.3)
\$150,000 and more	3 (18.7)
Not reported	1 (6.3)
Marital status, n (%)	
Married/Common law	11 (68.8)
Divorced/Separated/Never Married	5 (31.2)
Employment status, n (%)	
Employed	5 (31.3)
Long-term disabilities	3 (18.7)
Retired	8 (50.0)

French cognitive debriefing interviews. The final English version is presented in Appendix 1 and the French version in Appendix 2.

**Sleep.** For the English version, three different versions of the sleep item were asked to a total of seven participants

**Table 2.** English and French Item Development Through Cognitive Debriefing Interviews.

Revision	Participant number															
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
<b>Sleep</b>																
Problem identified with “promptly”					X											
Recommended changing to “quickly”																
Adjusted “promptly” to “quickly”/Recommended adding “I do not wake up at night” to response 1						X	X									
“I do not wake up at night” was added at the end of response 1—to account for not all individuals waking up at night								✓	✓	✓	✓					
French—Item translation clear												✓	✓	✓		
<b>Memory</b>																
Recommended using “I had no difficulty” rather than “I never had difficulty”	X															
Also recommended “I never had difficulty” rather than “I had no difficulty”—matches the other responses statements that are phrased as times		✓	✓	✓												
French—Item translation clear												✓	✓	✓	✓	
<b>Walking</b>																
Problem identified with the word “briskly”.	X															
Recommended adding “without a walking aid” at the end of response 1 for clarity																
“briskly” changed to “easily”		X	X	X	X	X										
Also recommended adding “without a walking aid” at the end of response 1 for clarity																
Problem with the example “within work environment” as this is not relevant to everyone—removed this from item																
“Without a walking aid” added at the end of response 1							✓	✓								
Problem identified with walking setting and it not being consistent throughout (outside, recreation, sports)—walking around the house not mentioned									X	X	X					
Item clear and no issue identified with the setting of the walking as the item does not focus on one specific setting and does not aim to assess walking at home. <sup>a</sup>												✓	✓	✓		
French—Item translation clear														✓	✓	✓
<b>Fatigue</b>																
Recommended adding an example such as “nap” to the word “rest”	X	X														
“Nap” added beside “rest”			X	X												
No examples added to “rest”/“rest” understood and meaning clear without examples					✓	✓	✓									
French—The question stem is missing “niveau de”												X				
French—Item translation clear/Preference of using “Je me suis senti tellement fatigué que” rather the “fatigué à un point tel que”/“fatigué à un point tel que” kept in the translation <sup>b</sup>												✓	X/✓	✓	✓	
<b>Mood</b>																
Problem identified with “sad or depressed”—not representative of mood/Recommended switching the question to a more positive lens	X															
Problem identified with “sad or depressed”—depression is not a choice/Problem identified with the first response option “all the time”.		X														
The question was adjusted from “sad or depressed” to “happy or positive”/“All the time” changed to “In general”			X	X	X											
Recommended “most of the time” and “some of the time” be moved to the start of response options 2 and 3 for consistency																
“Most of the time” and “some of the time” moved to the start of response options 2 and 3						✓	✓	✓								
French—a problem identified with the word “positif” in French/ Alternatives suggested included “de bonne humeur” “dans un état d’esprit”; however, these changed the meaning												X				

(continued)

**Table 2.** (continued)

Revision	Participant number															
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
French—"la plupart du temps" switched to "Souvent" in response 2/ Response option 2 new version proposed and implemented: "En général, je me suis senti heureux ou positif à exception de quelques instances"														X		
French—Item translation clear														✓	✓	✓
English version adjusted to match the French version																
Tremor	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
"I had no" changed to "I never had"								✓	✓	✓	✓					
French—Item translation clear														✓	✓	✓
Dexterity	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
Problem identified with the question not specifying the use of assistance/Problem identified with the inclusion of "write" <sup>c</sup>								✓	✓	X	✓					
"Without assistance" added to the question stem												X				
"write" deemed very important as part of dexterity—"write" kept <sup>a</sup>												✓	✓	✓		
French—Item translation clear												✓	✓	✓		

<sup>a</sup>Interviewed bilingual participants.

<sup>b</sup>#13, #14, and #15 accepted the revised French version but #14 preferred to use "Je me suis senti tellement fatigué que" rather the "fatigué à un point tel que"; however, the expert group decided to keep "fatigué à un point tel que" due to the clarity and length of the sentence.

<sup>c</sup>#7, #8, and #10 accepted the original version but the feedback was brought up in an interview with #9.

regarding word clarity and appropriateness of response options. A respondent picked up a problem with the word "promptly" from the prototype version and recommended changing this word to "quickly." With this change, two other participants recommended adding "I do not wake up at night" to account for issues with sleep quality. After this revision, three people in a row accepted the final, which was then included in the final PB-PDI. For the French version, participants had no issues with item clarity or wording.

**Memory.** One person recommended using the phrase "I had no difficulty" rather than "I never had difficulty"; however, multiple participants preferred keeping "I never had difficulty" as this was consistent with other response options (never, rarely, sometimes, and often). Thus, "I never had difficulty" was endorsed for the response option of the item, memory. Furthermore, participants preferred keeping the examples in the question, such as "forgetting medical appointments, taking your medication, what you were supposed to buy at the store." The French version of the item was endorsed by three participants in a row and no issues were identified.

**Walking.** A respondent identified an issue with the use of "briskly" in the walking item. Other participants suggested changing the word "briskly" to "easily." In addition, they suggested removing the example "within work environment" from the item because walking within a work environment was not relevant to the older adult population. Participants suggested adding "without a walking aid" at the end of the first response option. For consistency between the response options, without or with a walking aid was added at the

end of the all of the response options. Participants who were interviewed in French indicated that the translation of the item and its response options were clear, and they did not have changes to make.

**Fatigue.** During the English interviews, two participants recommended adding "nap" as an example to the word "rest" in the response option. However, five participants commented that "rest" could be easily understood by each participant with reference to their own resting methods such as meditating, laying down on a couch/bed, watching television, reading a book, or napping, and that the item should not include examples. This resulted in no examples being included in the response option for the fatigue item. For the French version, although the fatigue item was overall clearly understood, three participants recommended adding "niveau de" to the question stem for better language equivalence.

**Mood.** During the English interview, participants discussed concerns with the words "sad or depressed" as a representation of one's mood. This was mainly because participants did not always relate to being depressed, and the question made participants feel like they were responding to a negatively worded question and one that makes certain assumptions. Instead, participants suggested taking a positive lens and using words such as "happy," to capture one's mood. Two suggestions came out from the participants regarding switching words in the response options. One person identified the problem with the word "positif," and the other one suggested that the word "la plupart du temps" switched to "souvent." However, researchers decided to English version adjusted

to match the French version instead because these words could be changed the meaning.

**Tremor.** For the item on tremor, people preferred using “I never had” as this fit the other response options (never, rarely, sometimes, and often), instead of “I had no.” With this minor revision, all participants accepted the item and had no concerns with it. Three people provided feedback on the French version of the item; the response options were very clear, and no comprehension issues were identified.

**Dexterity.** For the dexterity item, three participants responded that the response options were clear and easy to understand. However, one participant highlighted that the question was not specifying the use of assistance. Furthermore, they suggested that “writing” should be included as an example in the question, as it is an indicator of fine motor skills among people with PD. These changes were incorporated into the question and endorsed by three participants afterwards. Participants who were interviewed in French indicated that the translation of the item and its response options were clear, and they did not have changes to make.

**Recall Period.** Throughout the questionnaire, the recall period was also assessed. Participants were asked which time frame was more representative of their health when recalling their answers. Participants answered that they were able to think back on their experiences in 2 weeks and believed this was an appropriate time frame because it was more representative of their present experience and easy to recall.

**Response Rating.** The VAS was used to assess the discriminative capacity of the response options of each item in the PB-PDI. The mean VAS values of response options 2 and 3 are shown in Table 3. Response options 1 and 4 were anchored at 0 and 10, respectively. For all seven items, all response options demonstrated an increasing trend in VAS values when going from response option 2 (range: 2.8–3.0) to 3 (range: 6.1–7.2).

**Table 3.** Mean VAS Values for Response Options 2 and 3.

	Response option 1	Response option 2 Mean $\pm$ SD	Response option 3 Mean $\pm$ SD	Response option 4
Sleep	0	2.9 $\pm$ 0.7	6.1 $\pm$ 1.8	10
Memory	0	3.0 $\pm$ 0.8	7.2 $\pm$ 0.3	10
Walking	0	2.9 $\pm$ 1.0	6.8 $\pm$ 1.4	10
Fatigue	0	2.8 $\pm$ 1.3	6.3 $\pm$ 1.8	10
Mood	0	2.9 $\pm$ 0.6	6.9 $\pm$ 1.0	10
Tremor	0	2.9 $\pm$ 0.6	6.7 $\pm$ 0.7	10
Dexterity	0	2.9 $\pm$ 0.4	6.9 $\pm$ 9.5	10

## Discussion

This study is part of a larger project to develop a new measure of HRQoL, the PB-PDI, in English and French. The PB-PDI includes a total of seven items with four response levels each (ie, sleep, memory, walking, fatigue, mood, tremor, and dexterity).<sup>18</sup> This study performed cognitive interviews with people with PD to examine item clarity, appropriateness of the response options and recall period, and finalize the PB-PDI in English and French.

The participants considered all seven items in the PB-PDI relevant to their experiences with PD, and all items were endorsed. Throughout the interviews, participants highlighted several terms that required revision to the response options. These terms included “promptly” (item, Sleep), “briskly” (item, Walking), and “sad or depressed” (item, Mood). Thus, in the final version, the word “promptly” was changed to “quickly,” and the term “briskly” was edited to “easily.” These comments suggested a problem with the use of vocabulary. From the interviews, we were also able to observe how important destigmatizing life with PD is to patients. For example, participants preferred that the question about mood be reworded in terms of “happy or positive” rather than “sad or depressed.” People also discussed whether to include examples in the questions or response options. Generally, adding an example would help participants understand items, as in the case of the Memory and Dexterity items. However, sometimes, adding examples was not preferred because it could lead to a restriction of the construct that each item is trying to capture. For example, some respondents suggested adding “nap” as an example of “rest” to the item Fatigue; however, others disagreed because they thought each participant might have their own resting methods. Participants also recommended to use phrases as times (ie, never, rarely, sometimes, often) for the response options, and this was adjusted accordingly.

After the English interviews, a total of five French cognitive debriefing interviews were conducted. Participants had no issues with clarity or translation revisions for the five items (ie, sleep, memory, walking, tremor, dexterity); however, two items (ie, fatigue, and mood) required minor revisions. For example, in the item Fatigue, “niveau de” (level of) was added to the question. Most comments were related to improving the language equivalence of the questions and response options.

People with PD selected a 2-week timeframe for the PB-PDI recall period. In previous research, the degree to which repeated HRQoL measurements in the same patient results in similar answers is usually investigated at 1–2-week intervals.<sup>21,22</sup> According to this previous finding, the PB-PDI, our newly developed HRQoL measurement can be a beneficial tool for evaluating treatments and estimating QALYs for people with PD. Moreover, people with PD may suffer from cognitive impairments even before PD is diagnosed. For this reason, longer recall periods could lead to people having difficulty remembering events which can lead to recall bias affecting HRQoL assessment.

This cognitive interview stage was an important part of the development process for the new PD-specific HRQoL measure. Our newly developed PB-PDI is short and has seven items. In clinical practice, some PD-specific scales are currently used but contain various limitations including having too long of a recall period, not focusing enough on non-motor symptoms, and being time-consuming to complete.<sup>23</sup> Our new measure, the PB-PDI is a PRO measure, and all items in our study were reviewed by the target population. Exploring patient voices is of great importance when developing a new HRQoL questionnaire.<sup>24,25</sup>

Cognitive interviews with people with PD allowed us to clarify items, make the items more applicable in terms of their instructions and response options, and ensure that the meaning of items was equivalent in English and French.

## Limitations

One possible limitation of our study is that the participants were recruited from a single region in Canada where patients received services within a publicly funded healthcare setting. People with PD from other types of healthcare settings may have different perspectives and experiences in HRQoL. While our participants might be from diverse cultures, we did not collect culture-specific information. Furthermore, participants were only asked about the clarity of items and response options, and the recall time period of the seven items in PB-PDI, but we did not ask about the acceptability or feasibility of the measure.

## Conclusion

In conclusion, this study finalized the items of the PB-PDI in English and French. The PB-PDI is different from existing PD scales because it will provide a single index of HRQoL that is anchored from 0 (dead) to 1 (full health), which in turn can be used to perform a cost-utility analysis. The next phase of this study will be to elicit preference weights for the PB-PDI and develop a scoring algorithm. The PB-PDI and its scoring algorithm may be used by researchers and policymakers when making treatment decisions for people with PD.<sup>26</sup> Preference weights for the PB-PDI will be generated using the Discrete Choice Experiment. A series of plausible health states from the PB-PDI will be provided to participants, and they will be asked to choose their preferred health status. In addition, evaluating the measurement properties of the PB-PDI will be the next step of our study. Future work will assess the test-retest reliability, determine the Minimal Detectable Change (MDC) value, and evaluate convergent and predictive validity. Furthermore, before using the PB-PDI in clinical practice, conducting a pilot test of the PB-PDI with a small group of PD patients would be valuable to gain feedback on the acceptability and feasibility of

the measure. The final PB-PDI may be used for monitoring the effectiveness of interventions and guiding practitioners to make appropriate healthcare plans<sup>26</sup> for their patients with PD.

## Appendix I

### Preference-Based PD Index of HRQoL—English

Under each heading, please choose the option that best describes your health **during the past two weeks** as it relates to your Parkinson's disease.

#### 1) Sleep

Describe your ability to sleep.

- When I woke up at night I could always get back to sleep quickly or I did not wake up
- When I woke up at night I often got back to sleep quickly
- When I woke up at night I sometimes got back to sleep quickly
- When I woke up at night I rarely got back to sleep quickly

#### 2) Memory

Describe your ability to remember things (for example, remembering medical appointments, taking your medication, or what you were supposed to buy at the store).

- I never had difficulty remembering
- I rarely had difficulty remembering
- I sometimes had difficulty remembering
- I often had difficulty remembering

#### 3) Walking

Describe your ability to walk.

- I could walk easily for recreation or sports without a walking aid
- I could walk to and from transportation or within a public building without a walking aid
- I could walk to and from transportation or within a public building with a walking aid
- I could only take a few steps or I used a wheelchair

#### 4) Fatigue

Describe your fatigue.

- I never felt so tired that I had to rest during the day
- I felt so tired that I had to have one rest during the day
- I felt so tired that I had to rest more than once a day
- I felt so tired that I had to rest most of the day

#### 5) Mood

Describe your mood.

- In general, I felt happy or positive

- In general I felt happy or positive with the exception of a few instances
- Some of the time, I felt happy or positive
- I rarely or never felt happy or positive

### 6) Tremor

Describe your tremors.

- I never had tremors
- I had tremors that did not interfere with my activities
- I had tremors that sometimes interfered with my activities
- I had tremors that often interfered with my activities

### 7) Dexterity

Describe your ability to use your hands without assistance (for example, to feed yourself, brush your teeth, button your shirt, write or type).

- I had no difficulty with these activities
- I had a little difficulty with these activities
- I had some difficulty with these activities
- I had a lot of difficulty with these activities

## Appendix 2

### Preference-Based PD Index of HRQoL

Pour chaque catégorie, veuillez choisir l'option qui décrit le mieux votre santé **au cours des deux dernières semaines** en ce qui concerne votre la maladie de Parkinson.

L'utilisation du genre masculin ne vise qu'à alléger le texte et se fait sans discrimination.

#### 1) Sommeil

Décrivez votre capacité à dormir.

- Quand je me réveillais pendant la nuit je pouvais toujours me rendormir rapidement ou je ne me réveillais pas
- Quand je me réveillais pendant la nuit je pouvais souvent me rendormir rapidement
- Quand je me réveillais pendant la nuit je pouvais parfois me rendormir rapidement
- Quand je me réveillais pendant la nuit je pouvais rarement me rendormir rapidement

#### 2) Mémoire

Décrivez votre capacité à vous souvenir (par exemple, se rappeler des rendez-vous médicaux, prendre ses médicaments, se rappeler des articles à acheter au magasin.)

- Je n'ai jamais eu de la difficulté à me souvenir
- J'ai rarement eu de la difficulté à me souvenir
- J'ai parfois eu de la difficulté à me souvenir
- J'ai souvent eu de la difficulté à me souvenir

#### 3) Marche

Décrivez votre capacité à marcher.

- J'ai pu facilement faire de la marche comme loisir ou comme sport sans aide à la marche
- J'ai pu marcher pour me rendre à un transport ou dans un bâtiment public sans aide à la marche
- J'ai pu marcher pour me rendre à un transport ou dans un bâtiment public avec une aide à la marche
- Je n'ai pu marcher que quelques pas ou j'utilisais un fauteuil roulant

#### 4) Fatigue

Décrivez votre niveau fatigue.

- Je ne me suis jamais senti fatigué à un point tel que j'ai eu besoin de me reposer pendant la journée
- Je me suis senti fatigué à un point tel que j'ai eu à me reposer une fois pendant la journée
- Je me suis senti fatigué à un point tel que j'ai eu à me reposer plus d'une fois pendant la journée
- Je me suis senti fatigué à un point tel que j'ai eu à me reposer une grande partie de la journée

#### 5) Humeur

Décrivez votre humeur.

- En général, je me suis senti heureux ou positif
- En général, je me suis senti heureux ou positif sauf pour quelques moments
- Parfois, je me suis senti heureux ou positif
- Je me suis rarement ou jamais senti heureux ou positif

#### 6) Tremblement

Décrivez vos tremblements.

- Je n'ai jamais eu de tremblements
- J'ai eu des tremblements qui n'ont pas eu d'effets sur mes activités
- J'ai eu des tremblements qui ont parfois eu un effet sur mes activités
- J'ai eu des tremblements qui ont souvent eu un effet sur mes activités

#### 7) Dexterité

Décrivez votre capacité à utiliser vos mains sans assistance (par exemple, pour vous nourrir, pour brosser vos dents, pour boutonner votre chemise, pour écrire à la main ou sur un clavier).

- Je n'ai pas eu de difficultés avec ces activités
- J'ai eu peu de difficultés avec ces activités
- J'ai eu quelques difficultés avec ces activités
- J'ai eu beaucoup de difficultés avec ces activités



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The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.


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