

Supplementary Material

What Patients Say: Large-scale Analyses of Replies to the Parkinson's Disease Patient Report of Problems (PD-PROP)

Supplementary Table 1. The Parkinson's Disease Patient Report of Problems as implemented in Fox Insight

<p>1 What is the most bothersome problem for you due to your Parkinson's disease?</p> <p>1.1 In what way does this problem bother you (by affecting your everyday functioning or ability to accomplish what needs to be done)?</p> <p>1.2 How much (severely) does this problem bother you by limiting your functioning? 0 = Not at all 1 = Mildly (minimally or rarely) 2 = Moderately (more often than not) 3 = Severely (plenty or all of the time)</p>
<p>2 What is the 2nd most bothersome problem for you due to your Parkinson's disease?</p> <p>2.1 In what way does this problem bother you (by affecting your everyday functioning or ability to accomplish what needs to be done)?</p> <p>2.2 How much (severely) does this problem bother you by limiting your functioning? 0 = Not at all 1 = Mildly (minimally or rarely) 2 = Moderately (more often than not) 3 = Severely (plenty or all of the time)</p>
<p>3 What is the 3rd most bothersome problem for you due to your Parkinson's disease?</p> <p>3.1 In what way does this problem bother you (by affecting your everyday functioning or ability to accomplish what needs to be done)?</p> <p>3.2 How much (severely) does this problem bother you by limiting your functioning? 0 = Not at all 1 = Mildly (minimally or rarely) 2 = Moderately (more often than not) 3 = Severely (plenty or all of the time)</p>
<p>4 What is the 4th most bothersome problem for you due to your Parkinson's disease?</p> <p>4.1 In what way does this problem bother you (by affecting your everyday functioning or ability to accomplish what needs to be done)?</p> <p>4.2 How much (severely) does this problem bother you by limiting your functioning? 0 = Not at all 1 = Mildly (minimally or rarely) 2 = Moderately (more often than not) 3 = Severely (plenty or all of the time)</p>
<p>5 What is the 5th most bothersome problem for you due to your Parkinson's disease?</p> <p>5.1 In what way does this problem bother you (by affecting your everyday functioning or ability to accomplish what needs to be done)?</p> <p>5.2 How much (severely) does this problem bother you by limiting your functioning? 0 = Not at all 1 = Mildly (minimally or rarely) 2 = Moderately (more often than not) 3 = Severely (plenty or all of the time)</p>

Supplementary Table 2. Domains, symptoms curated and their conceptual boundaries

Domain	Proposed patient reported symptom	Conceptual boundaries	
		Includes	Excludes
Tremor	tremor	oscillating, rhythmic involuntary movement of any body part	involuntary movements not specified as tremor or shaking, 'shakiness' describing an anxiety-related symptom
	internal tremor	invisible rhythmic sensation	shakiness' or 'jitteriness' reported to be due to anxiety, restlessness or skin-crawling sensation
Rigidity	stiffness	stiffness, rigidity, reduced range of movement	bending, foot/leg drag
Bradykinesia	slowness	slow limb or whole body movement	like a zombie/zombie-like
	facial expression	hypomimia, facial dystonia	
Postural Instability	balance	Having difficulty maintaining balance while not being supported, includes falling and near falls, includes the sensation of difficulty maintaining balance, includes requiring support to maintain balance, tendency to trip	
	falls	Losing balance and being unable to recover, resulting in contact with the ground	near falls, tipping over, almost falling
	fear of falling	Fear of losing balance and being unable to recover, resulting in contact with the ground	falling
Gait	gait NOS	Abnormality of ambulation including abnormality of stride, stance, rhythm, reduced arm swing, reduced movements not due to freezing of gait	imbalance, freezing of gait
	freezing of gait	Freezing, failure to initiate or delay of initiation of movement, or arrest of ongoing movement, may be momentary, frozen foot	'fear of' freezing, festination
Dyskinesias	dyskinesias	unintentional dancing/swaying movement, usually related to medication ON time	
Fluctuations	off periods— medication related	Return of symptoms such as tremor, stiffness, freezing of gait, etc., prior to next medication dose. Mentions of wearing off	off periods with no mention of medication
	off periods— medication not mentioned	Occurrence of OFF periods without any specific trigger mentioned, Both OFF and ON and the cycling	emotional roller coaster, mentions of wearing off

		between the two which itself is bothersome to the patient	
	random off/unpredictable off	Unpredictability, inconsistency of off periods (in relation to meds or otherwise). No recognizable pattern with respect to medication schedule.	
	meds not working NOS	lack of meaningful effect of a dose of dopaminergic medication. Includes meds taking longer to kick in than usual	
Other Motor	impaired dexterity/micrographia	impaired or slowed ability to do tasks requiring fine movement/fine motor skills or movement (of the hand) such as dressing, playing sports, writing, eating, typing, etc. May be due to tremor, rigidity, bradykinesia, or other issue. Small handwriting, shaky handwriting, illegible or messy handwriting not otherwise specified	
	dystonia	abnormal posture of a body part due to involuntary muscle contraction, includes cramping, and leaning	stiffness, rigidity when dystonia is not reported or mentioned. Cramping in the context of abdominal pain, abdominal fullness/constipation/gastrointestinal, stomach.
	posture	deviation of trunk; any change in posture resulting in person being not fully upright	
	speech	abnormality of voice or speech, including slurred speech, low speech volume, festinating (accelerating) speech, hesitancy of starting speech, voice tremor/vocal tremor	language problems such as word-finding difficulty
Sleep	excessive daytime sleepiness	Urge or need to sleep in situations when is sleep not desired or appropriate, includes voluntary or involuntary napping, intentional or unintentional sleep during the day, or daytime sleepiness due to medication or other triggers	tiredness/fatigue with no mention of need to sleep or nap
	sleep onset insomnia	Difficulty falling asleep at the beginning of the sleep period regardless of cause	
	sleep maintenance insomnia	Awakening during the night with difficulty falling asleep again regardless of cause	awakenings (e.g., due to trips to the bathroom) without difficulty falling back asleep, up and down all night

	early morning awakening	Waking up earlier than desired and not being able to fall back to sleep again regardless of cause	
	poor sleep quality unspecified	Any trouble sleeping not specified as "sleep onset" or "sleep maintenance" insomnia or early morning awakening; example would be "don't sleep well" or "poor sleep" or "can't sleep"	
	RLS/restlessness	Urge to move that is relieved by movement	dyskinesias
	RBD-like symptoms	Acting out dreams, movements, or vocalizations during sleep; may only be aware due to partner report; explicit reports of REM sleep issues; night terrors	moving in sleep without further specification
	parasomnia unspecified	sleep talking, sleep walking	dream enactment, sleep paralysis
	dreams	Any reports of dreams including vivid or intense, detailed dreams; dreams that seem real, nightmares	dream enactment
Fatigue	physical fatigue	Exhaustion or tiredness of the body	
	mental fatigue	A sense of mental exhaustion not stated to be explained by drug effects, other medical, or psychiatric disorders. Includes feeling weary or exhausted during an intellectually challenging task with a decreased capacity to initiate or sustain cognitively challenging activities.	sleepiness with no mention of being tired
Cognition	memory	Impairment of memory including difficulty remembering information; learning new information; orientation to time, place	the term "having to remember"
	concentration/attention	Difficulty concentrating or paying attention; sustaining focus	
	cognitive slowing	Slowing or impairment of mental processing. Includes difficulty keeping up with conversations, slowness to respond, mental fatigue	confusion, 'brain fog', mental sharpness;
	language/word finding	difficulty understanding conversation; expressing oneself; difficulty speaking words that are being thought of. difficulty understanding what is being read/reading	difficulty understanding due to hearing impairment

	mental alertness/awareness	fluctuating alertness; fluctuations in/variable attention; zoning out, brain fog, confused thoughts, reduced mental sharpness	cognitive/mental slowing
	visuospatial abilities	difficulty judging distances or depth; navigating 3-dimensional situations; orienting oneself in space; identifying visual and spatial relationships among objects; trouble navigating closed or indoor spaces that are familiar	freezing in doorways or thresholds.
	executive abilities/working memory	difficulty planning or executing tasks; multi-tasking; switching from one cognitive task to another, trouble following directions or instructions; problem solving; decision making; sequencing; learning new skills	
	cognitive impairment NOS	Cognitive complaint not clearly fitting into another category. Could include confusion, muddled, mixed up	
Affect/Motivation/ Thought- Perception/Other Psychiatric	depressive symptoms	Feelings of sadness or hopelessness. Includes expressions of guilt, worthlessness, thoughts of death, suicide, or suicide plans	depressing, Discouraged, helpless
	death and suicidal ideation	thoughts of wanting to die, suicide, or a suicide plan	thoughts of NOT wanting to die (don't want to die), afraid/scared/fear of dying/death
	apathy	Apathy, a lack of desire, interest, or motivation to complete or participate in socialization, tasks, or other activities of daily living.	
	anxiety/worry	Excessive fear, nervousness or worry. Includes phobias, panic attacks, anxiety. Also includes fear of something	
	delusions/psychosis	false beliefs, mentions of psychosis	Paranoia
	loneliness/isolation	Feeling of being alone or isolated, feeling abandoned, effecting social life/interaction	
	impulse control	Difficulty controlling emotions or behaviors. Behavior done in excess/repetitively/compulsively and not typical for the person. Doing things before thinking. Includes urges to do things that are difficult to control, such as compulsive actions, and failure to	

		resist temptations that may be harmful such as shopping, gambling, eating, sexual behavior	
	hallucinations/illusion/ presence/passage	Seeing, hearing, smelling, tasting or feeling things that are not present. Includes sensations of someone being nearby, or passing by. Illusions: misinterpretation of an actual external stimulus (object misidentification or distortion)	
	pseudobulbar affect	uncontrollable laughing or crying, often unprovoked or provoked by something small	
	negative emotions or cognition NOS	Undesirable emotions or cognitions. Includes anger, frustration, helplessness, discouragement, feeling negative, negative outlook, pessimism, low self-esteem, lack of confidence, etc. Includes external expression of being easily annoyed or angered, the level of reaction exceeding what is warranted. (Irritability) Also, includes internal experience of being upset or annoyed, because of inability to change or achieve something. Also includes self-reported frustration, embarrassment, and poor body image due to PD symptoms. Changes in behaviors, thoughts, or emotional patterns. Includes loss of interest/uninterested, being unmotivated. Could be due to any trigger such as motor or non motor (cognitive or sleep or other.)	Negative emotions related to depression, expressions of guilt, worthlessness, thoughts of death, suicide, or suicide plans.
Pain	pain/discomfort	pain/ache due to any cause, including cramp. Includes uncomfortable feelings not described as pain, neuropathy	
	cramp or spasm	involuntary muscle contraction that is uncomfortable	
	headache	head pain or discomfort	
Autonomic Dysfunction	bowel incontinence	loss of control of bowel leading to bowel accidents	
	bowel urgency	Need to get to the toilet quickly to pass stool to avoid bowel accidents. May coexist with but is distinct from bowel incontinence	
	altered bowel frequency	Infrequent or difficult passage of stools including obstruction, a need to pass stool frequently, constipation	

bloating/feeling full	A feeling of fullness, tightness in the abdomen with distention. Includes gastroparesis, feeling bloated	
abdominal discomfort NOS	pain or discomfort attributed to GI tract. Includes digestive issues	bloating
bladder incontinence	Complete or partial loss of bladder control, with or without a trigger (e.g., sneezing, stress), includes incontinence	
excessive sweating	sweating more than expected	anxiety manifest as sweating, sweating caused by heat or activity
frequent urination	A need to pass urine more often than desired	urinary incontinence with no reference to urgency
lightheadedness/dizziness	A sense of lightheadedness or dizziness including from upon sitting from lying or upon standing from sitting. Also includes orthostatic hypotension.	-
swallowing problems	Difficulty getting food or liquids to go down, coughing on food or liquids	
temperature dysregulation	feeling excessively hot or cold in any part of the body	
sexual dysfunction	loss of sexual interest or difficulty with sexual activity	
diarrhea	loose bowels, watery bowel movements	increased frequency of bowel movements without mention of loose consistency, incontinence of stool without mention of loose consistency
nausea	a feeling of illness in the stomach with the sensation that one may vomit,	excludes bloating, heavy feeling in abdomen, throw up <near> lying down

NOS, not otherwise specified; RLS, restless legs syndrome; RBD, REM behavior disorder

Supplementary Table 3. Symptoms whose curation samples were enriched with closely-related symptoms and the enriching symptoms.

Symptoms Enriched	Enriched with
Memory	All Other Cognition Symptoms
Depressive Symptoms	Apathy Negative Emotions Nos
Cognitive Slowing	All Other Cognition Symptoms
Visuospatial Abilities	All Other Cognition Symptoms
Anxiety/Worry	Internal Tremor
Apathy	Depressive Symptoms Negative Emotions Nos
Concentration/Attention	All Other Cognition Symptoms
Executive Abilities_Working Memory	All Other Cognition Symptoms
Language/Word-Finding	All Other Cognition Symptoms
Personality And Behavior Changes Nos	Negative Emotions Nos
Mental Alertness/Awareness	All Other Cognition Symptoms
Tremor	Dyskinesia
Stiffness	Slowness
Internal Tremor	Anxiety
Dyskinesias	Tremor
Falls	Balance Fear Of Falling
Fear Of Falling	Balance Falling
Off Periods_Medication Related	Off Periods_Medication Not Mentioned Dose Failure
Off Periods_Medication Not Mentioned	Random Off_Unpredictable Off Off Periods_Medication Related
Slowness	Stiffness
Gait Nos	Freezing Of Gait
Bladder Incontinence	Frequent Urination
Bloating/Feeling Full	Abdominal Discomfort Nos
Bowel Incontinence	Altered Bowel Frequency
Sleep Onset Insomnia	Sleep Maintenance Insomnia Early Morning Awakening
Dreams	Poor Sleep Quality Rbd-Like Symptoms Parasomnia Unspecified
Early Morning Awakening	Sleep Maintenance Insomnia Sleep Onset Insomnia
Bowel Urgency	Poor Sleep Quality
RBD Like Symptoms	Altered Bowel Frequency Dreams

Sleep Maintenance Insomnia	Sleep Onset Insomnia
	Early Morning Awakening
Frequent Urination	Poor Sleep Quality
Parasomnia Unspecified	Bladder Incontinence
	RBD-Like Symptoms
	Dreams
Excessive Daytime Sleepiness	Fatigue
Mental Fatigue	Excessive Daytime Sleepiness