ICHOM

International Consortium for
Health Outcomes Measurement

PARKINSON'S DISEASE
DATA COLLECTION REFERENCE GUIDE

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Measuring
results
that matter

Doing
hobbies

Parkinson's Disease

ICHOM

PARKINSON'S DISEASE

We are thrilled that you are interested in measuring outcomes for your Parkinson's Disease patients according to ICHOM standards. It is our hope that this Reference Guide will facilitate the process of implementing our Standard Set and ensure collection of comparable data for global benchmarking and learning.

Introducing ICHOM and the Reference Guide

ICHOM brings together patient representatives, clinician leaders, and registry leaders from all over the world to develop Standard Sets, comprehensive yet parsimonious sets of outcomes and case-mix variables we recommend all providers track.

Each Standard Set focuses on patient-centered results, and provides an internationally-agreed upon method for measuring each of these outcomes. We do this because we believe that standardized outcomes measurement will open up new possibilities to compare performance globally, allow clinicians to learn from each other, and rapidly improve the care we provide our patients.

Our Standard Sets include initial conditions and risk factors to enable meaningful case-mix adjustment globally, ensuring that comparisons of outcomes will take into account the differences in patient populations across not just providers, but also countries and regions. We also include high-level treatment variables to allow stratification of outcomes by major treatment types. A comprehensive data dictionary is included in the appendix.

Working Group Members for Parkinson's Disease

The following individuals dedicated both time and expertise to develop the ICHOM Standard Set for Parkinson's Disease in partnership with ICHOM, under the leadership of Dr. Ryan Uitti, Professor of Neurology at the Mayo Clinic in Florida.

Canada
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Germany
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United Kingdom
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United States
Shyamal Mehta
Ryan Uitti
Daniel Weintraub
Bill Wilson

Supporting Organizations

We are grateful to the International Association for Parkinsonism and Related Disorders for their endorsement of this set.

Thank you.

Conditions and Treatment Approaches Covered for Parkinson's Disease

For Parkinson's Disease, the following conditions and treatment approaches (or interventions) are covered by our Standard Set.

Conditions	Idiopathic Parkinson's Disease
Treatment Approaches	Pharmacotherapy | Behavioral Therapy | Exercise-Based Therapy | Deep Brain Stimulation | Infusion/Injection-Based Delivery

ICHOM Standard Set for Parkinson's Disease

Case-Mix Variables

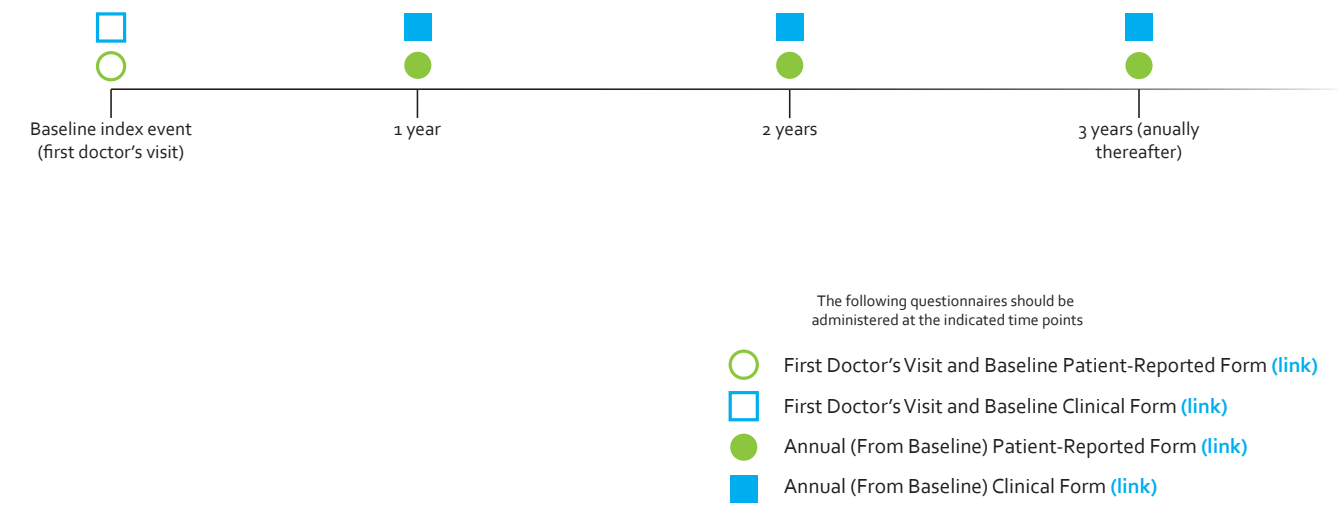| Patient Population	Measure	Supporting Information	Timing	Data Source
Demographic Factors				
All patients	Age	Date of birth	First doctor's visit	Clinical or patient-reported
	Sex	Sex at birth		
	Level of education	Level of schooling completed	Baseline and annually	Patient-reported
	Living status	Living arrangements		
	Marital Status	Relationship status		
Baseline Clinical Status				
All patients	Depression before PD diagnosis	N/A	First doctor's visit	Patient-reported
	Anxiety before PD diagnosis	N/A		
	REM Sleep Behavior Disorder before PD diagnosis	N/A		
	Age at PD diagnosis	N/A		
	Age at PD onset	N/A		
	Comorbidities	Modified Self-administered Comorbidity Questionnaire (SCQ)	Baseline and annually	

Treatment Variables

Patient Population	Measure	Supporting Information	Timing	Data Source
All patients	Treatment type	N/A	Annually	Clinical

Outcomes

Patient Population	Measure	Supporting Information	Timing	Data Source
Cognitive and Psychiatric Functioning				
All patients	Cognitive impairment	Tracked via MDS-UPDRS	Baseline and annually	Clinical
	Hallucinations and psychosis			
	Depressed mood			
	Anxious mood			
	Apathy			
	Features of dopamine dysregulation syndrome			
Non-Motor Aspects of Experiences of Daily Living				
All patients	Sleep problems	Tracked via MDS-UPDRS	Baseline and annually	Patient-reported
	Daytime sleepiness			
	Pain and other sensations			
	Urinary problems			
	Constipation problems			
	Light headedness on standing			
	Fatigue			
	Sexual function	Tracked via NMSQ		
	Sweating			
Motor Aspects of Experiences of Daily Living				
All patients	Speech	Tracked via MDS-UPDRS	Baseline and annually	Patient-reported
	Saliva and drooling			
	Chewing and swallowing			
	Eating tasks			
	Dressing			
	Hygiene			
	Handwriting			
	Doing hobbies and other activities			
	Turning in bed			
	Tremor			
	Getting out of bed, a car, or a deep chair			
	Walking and balance			
	Freezing			
Overall Health Status				
All patients	Ability to work	Related to Parkinson's Disease	Baseline and annually	Patient-reported
	Hospital admissions	Number of admissions and relatedness to Parkinson's Disease		
	PD-related quality of life	Tracked via PDQ-8		
	Falls	Did you suffer a bone fracture as a result?		
MDS-UPDRS: Movement Disorder Society; NMSQ: Non-Motor Symptoms Questionnaire; PDQ-8: Parkinson's Disease Quality of Life Questionnaire				

Follow-Up Timeline and Sample Questionnaires

The following timeline illustrates when Standard Set variables should be collected from patients, clinicians, and administrative sources. Links to the sample questionnaires may be found in the legend below.

Baseline index event (first doctor's visit)	1 year	2 years	3 years (anually thereafter)

The following questionnaires should be administered at the indicated time points

○ First Doctor's Visit and Baseline Patient-Reported Form **(link)**

☐ First Doctor's Visit and Baseline Clinical Form **(link)**

● Annual (From Baseline) Patient-Reported Form **(link)**

■ Annual (From Baseline) Clinical Form **(link)**

Collecting Patient-Reported Outcome Measures

Parkinson's Disease Survey Used	Licensing Information	Scoring Guides
Movement Disorder Society (MDS-UPDRS) 　　Part I: Non-Motor Aspects of Experiences of Daily Living (nM-EDL). Both clinical- and patient-reported portions 　　Part II: Motor Aspects of Experiences of Daily Living (M-EDL). Patient-reported	The MDS-UPDRS requires a license. Please visit **https://mds.movementdisorders.org/publications/rating_scales/request_form.php** for the permission request form.	See first link at left
International Parkinson's and Movement Disorders Society (IPMDS) Non-motor symptoms questionnaire (NMSQ)	The MDS-UPDRS requires a license. See first link above for the permission request form.	See first link at top left
Parkinson's Disease Quality of Life Questionnaire (PDQ-8)	The PDQ-8 requires a license. Please visit **http://isis-innovation.com/outcome-measures/parkinsons-disease-questionnaire-pdq-39-pdq-8** for the license request form.	See first link at left

The Growing ICHOM Community

By implementing the ICHOM Standard Sets, you become part of an expanding, international community of innovative health care providers dedicated to improving value for patients. Already, more than 40 institutions from nearly 20 countries have begun measuring outcomes according to ICHOM standards. To learn more about how ICHOM can assist your organization in implementing outcome measurement, contact us at **implement@ichom.org**, or visit **http://www.ichom.org/measure**.

Appendix

Introduction to the Data Dictionary

This data dictionary is designed to help you measure the ICHOM Parkinson's Disease Standard Set as consistently as possible to the Working Group recommendation. ICHOM is actively preparing for benchmarking efforts based on this data, and all data submitted for comparisons will need to be transformed into the following data structure if not already structured as such. **We are happy to provide an Excel version of this data dictionary for technical use.**

Please timestamp all variables. Some Standard Set variables are collected at multiple timepoints, and we will ask you to submit these variables in a concatenated VARIABLEID_TIMESTAMP form for future analyses. For example, VARIABLEID_BASE (baseline); VARIABLEID_6MO (6 month follow-up); VARIABLEID_1YR (1 year follow-up), etc.

Case-Mix Variables

Variable ID:	N/A
Variable:	Patient ID
Definition:	Indicate the patient's medical record number
Supporting Definition:	This number will not be shared with ICHOM. In the case patient-level data is submitted to ICHOM for benchmarking or research purposes, a separate ICHOM Patient Identifier will be created and cross-linking between the ICHOM Patient Identifier and the medical record number will only be known at the treating institution
Inclusion Criteria:	All patients
Timing:	On all forms
Data Source:	Administrative or clinical
Type:	Numerical
Response Options:	According to institution

Demographic Factors

Variable ID:	AGE
Variable:	Age
Definition:	What is your date of birth?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	First doctor's visit
Data Source:	Clinical or patient-reported
Type:	Date by DD/MM/YYYY
Response Options:	DD/MM/YYYY

Variable ID:	SEX
Variable:	Sex
Definition:	Please indicate your sex at birth
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	First doctor's visit
Data Source:	Clinical or patient-reported
Type:	Single answer
Response Options:	1 = Male
	2 = Female

	999 = Undisclosed
Variable ID:	EDUCATION
Variable:	Educational level
Definition:	Please indicate highest level of schooling completed
Supporting Definition:	The level of schooling is defined in each country as per ISCED [International Standard Classification]
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = None
	1 = Primary
	2 = Secondary
	3 = Tertiary
Variable ID:	LIVING
Variable:	Living status
Definition:	Which statement best describes your living arrangements?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	1 = I live with partner/spouse/family/friends
	2 = I live alone
	3 = I live in a nursing home, hospital or other long term care home
	888 = Other
Variable ID:	MARITAL
Variable:	Marital status
Definition:	What is your relationship status?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Never married/partnered
	1 = Married/partnered
	2 = Divorced/separated
	3 = Widowed

Baseline Clinical Status

Variable ID:	DEP
Variable:	Depression before PD diagnosis
Definition:	Did your doctor ever diagnose you with depression prior to your Parkinson's Disease diagnosis?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	First doctor's visit
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = No
	1 = Yes
Variable ID:	ANXIETY
Variable:	Anxiety before PD diagnosis
Definition:	Did your doctor ever diagnose you with anxiety prior to your Parkinson's Disease diagnosis?
Supporting Definition:	N/A

Inclusion Criteria:	All patients
Timing:	First doctor's visit
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = No
	1 = Yes

Variable ID:	REM
Variable:	REM sleep behavior disorder before PD diagnosis
Definition:	Before you were diagnosed with Parkinson's Disease, had you ever been told, or suspected yourself, that you seem to "act out your dreams" while asleep (for example, punching, flailing your arms in the air, making running movements etc.)?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	First doctor's visit
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = No
	1 = Yes

Variable ID:	AGEDIAG
Variable:	Age at PD diagnosis
Definition:	At what age was your Parkinson's Disease diagnosed?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	First doctor's visit
Data Source:	Patient-reported
Type:	Numerical value
Response Options:	Numerical value of age in years

Variable ID:	AGEONSET
Variable:	Age at PD onset
Definition:	At what age did your Parkinson's Disease motor symptoms (e.g., rigidity, tremor, slowness of movement) start?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	First doctor's visit
Data Source:	Patient-reported
Type:	Numerical value
Response Options:	Numerical value of age in years

Variable ID:	COMORB
Variable:	Comorbidities
Definition:	Have you been told by a doctor that you have any of the following?
Supporting Definition:	Based upon the Self-administered Comorbidity Questionnaire (Sangha et al, 2003)
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Multiple answer
	Separate multiple entries with ";"
Response Options:	0 = I have no other diseases
	1 = Heart disease (For example, angina, heart attack, or heart failure)
	2 = High blood pressure
	3 = Leg pain when walking due to poor circulation
	4 = Lung disease (For example, asthma, chronic bronchitis, or emphysema)
	5 = Diabetes
	6 = Kidney disease
	7 = Liver disease
	8 = Problems caused by stroke
	9 = Disease of the nervous system (For example, multiple sclerosis)

10 = Other cancer
(within the last 5 years)
11 = Depression
12 = Arthritis

Treatment Variables

Variable ID:	MEDTHER
Variable:	Treatments received over the last 12 months: Medical therapy
Definition:	Indicate if the patient received medical therapy during the last 12 months
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Annually
Data Source:	Clinical
Type:	Single answer
Response Options:	0 = No
	1 = Yes

Variable ID:	BEHTHER
Variable:	Treatments received over the last 12 months: Behavioral therapy
Definition:	Indicate if the patient received behavioral therapy during the last 12 months
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Annually
Data Source:	Clinical
Type:	Single answer
Response Options:	0 = No
	1 = Yes

Variable ID:	EBTHER
Variable:	Treatments received over the last 12 months: Exercise-based therapy
Definition:	Indicate if the patient received exercise-based therapy during the last 12 months
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Annually
Data Source:	Clinical
Type:	Single answer
Response Options:	0 = No
	1 = Yes

Variable ID:	DBSTIM
Variable:	Treatments received over the last 12 months: Deep brain stimulation
Definition:	Indicate if the patient received deep brain stimulation during the last 12 months
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Annually
Data Source:	Clinical
Type:	Single answer
Response Options:	0 = No
	1 = Yes

Variable ID:	IITHER
Variable:	Treatments received over the last 12 months: Infusion/injection based delivery therapy
Definition:	Indicate if the patient received infusion/injection based delivery therapy during the last 12 months
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Annually
Data Source:	Clinical
Type:	Single answer
Response Options:	0 = No
	1 = Yes

Outcomes

Cognitive and Psychiatric Functioning

Variable ID:	MDSUPDRS_Q01
Variable:	Cognitive impairment
Definition:	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]
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Clinical
Type:	Single answer
Response Options:	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
Variable ID:	MDSUPDRS_Q02
Variable:	Hallucinations and psychosis
Definition:	1.2 HALLUCINATIONS AND PSYCHOSIS
	Instructions to examiner: 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.
	Instructions to patients [and caregiver]: Over the past week have you seen, heard, smelled or felt things that were not really there?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Clinical
Type:	Single answer
Response Options:	0 = Normal: No hallucinations or psychotic behavior
	1 = Slight: Illusions or non-formed hallucinations, but patient recognizes them without loss of insight
	2 = Mild: Formed hallucinations independent of environmental stimuli. No loss of insight
	3 = Moderate: Formed hallucinations with loss of insight
	4 = Severe: Patient has delusions or paranoia
Variable ID:	MDSUPDRS_Q03
Variable:	Depressed mood
Definition:	1.3 DEPRESSED MOOD

Instructions to examiner: 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.

Instructions to patients [and caregiver]: 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 to carry out your usual activities or to be with people?

Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Clinical
Type:	Single answer
Response Options:	0 = Normal: No depressed mood
	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
	2 = Mild: Depressed mood that is sustained over days, but without interference with normal activities and social interactions
	3 = Moderate: Depressed mood that interferes with, but does not preclude, the patient's ability to carry out normal activities and social interactions
	4 = Severe: Depressed mood precludes patient's ability to carry out normal activities and social interactions
Variable ID:	MDSUPDRS_Q04
Variable:	Anxious mood
Definition:	1.4 ANXIOUS MOOD

Instructions to examiner: 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.

Instructions to patients [and caregiver]: 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?

Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Clinical
Type:	Single answer
Response Options:	0 = Normal: No anxious feelings
	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
	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
	3 = Moderate: Anxious feelings interfere with, but do not preclude, the patient's ability to carry out normal activities and social interactions
	4 = Severe: Anxious feelings preclude patient's ability to carry out normal activities and social interactions
Variable ID:	MDSUPDRS_Q05
Variable:	Apathy
Definition:	1.5 APATHY

Instructions to examiner: 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.

	Instructions to patients [and caregiver]: Over the past week, have you felt indifferent to doing activities or being with people?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Clinical
Type:	Single answer
Response Options:	0 = Normal: No apathy
	1 = Slight: Apathy appreciated by patient and/or caregiver, but no interference with daily activities and social interactions
	2 = Mild: Apathy interferes with isolated activities and social interactions
	3 = Moderate: Apathy interferes with most activities and social interactions
	4 = Severe: Passive and withdrawn, complete loss of initiative
Variable ID:	MDSUPDRS_Q06
Variable:	Features of dopamine dysregulation syndrome
Definition:	1.6 FEATURES OF DOPAMINE DYSREGULATION SYNDROME
	Instructions to examiner: 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).
	Instructions to patients [and caregiver]: 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?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Clinical
Type:	Single answer
Response Options:	0 = Normal: No problems present
	1 = Slight: Problems are present but usually do not cause any difficulties for the patient or family/caregiver
	2 = Mild: Problems are present and usually cause a few difficulties in the patient's personal and family life
	3 = Moderate: Problems are present and usually cause a lot of difficulties in the patient's personal and family life
	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

Non-Motor Aspects of Experiences of Daily Living

Variable ID:	MDSUPDRS_Q07
Variable:	Sleep problems
Definition:	This questionnaire will ask you about your experiences of daily living.
	We are trying to be thorough, and some of these questions may therefore not apply to you now or ever. If you do not have the problem, simply mark Normal. Please read each one carefully and read all answers before selecting the one that best applies to you.
	We are interested in your average or usual function over the past week including today. Some patients can do things better at one time of the day than at others. However, only one answer is allowed for each question, so please select the answer

that best describes what you can do most of the time.

You may have other medical conditions besides Parkinson's disease. Do not worry about separating Parkinson's disease from other conditions. Just answer the question with your best response.

Use only the answers provided. Do not leave any blanks.

Your doctor or nurse can review the questions with you, but this questionnaire is for patients to complete, either alone or with their caregivers.

1.7 SLEEP PROBLEMS

Over the past week, have you had trouble going to sleep at night or staying asleep through the night? Consider how rested you felt after waking up in the morning

Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Normal: No problems
	1 = Slight: Sleep problems are present but usually do not cause trouble getting a full night of sleep
	2 = Mild: Sleep problems usually cause some difficulties getting a full night of sleep
	3 = Moderate: Sleep problems cause a lot of difficulties getting a full night of sleep, but I still usually sleep for more than half the night
	4 = Severe: I usually do not sleep for most of the night

Variable ID:	MDSUPDRS_Q08
Variable:	Daytime sleepiness
Definition:	1.8 DAYTIME SLEEPINESS
	Over the past week, have you had trouble staying awake during the daytime?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Normal: No daytime sleepiness
	1 = Slight: Daytime sleepiness occurs but I can resist and I stay awake
	2 = Mild: Sometimes I fall asleep when alone and relaxing. For example, while reading or watching TV
	3 = Moderate: I sometimes fall asleep when I should not. For example, while eating or talking with other people
	4 = Severe: I often fall asleep when I should not. For example, while eating or talking with other people

Variable ID:	MDSUPDRS_Q09
Variable:	Pain and other sensations
Definition:	1.9 PAIN AND OTHER SENSATIONS
	Over the past week, have you had uncomfortable feelings in your body like pain, aches, tingling or cramps?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Normal: No uncomfortable feelings
	1 = Slight: I have these feelings. However, I can do things and be with other people without difficulty
	2 = Mild: These feelings cause some problems when I do things or am with other people
	3 = Moderate: These feelings cause a lot of problems, but they do not stop me from doing things or being with other people

4 = Severe: These feelings stop me from doing things or being with other people

Variable ID:	MDSUPDRS_Q10
Variable:	Urinary problems
Definition:	1.10 URINARY PROBLEMS
	Over the past week, have you had trouble with urine control? For example, an urgent need to urinate, a need to urinate too often, or urine accidents?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Normal: No urine control problems
	1 = Slight: I need to urinate often or urgently. However, these problems do not cause difficulties with my daily activities
	2 = Mild: Urine problems cause some difficulties with my daily activities. However, I do not have urine accidents
	3 = Moderate: Urine problems cause a lot of difficulties with my daily activities, including urine accidents
	4 = Severe: I cannot control my urine and use a protective garment or have a bladder tube

Variable ID:	MDSUPDRS_Q11
Variable:	Constipation problems
Definition:	1.11 CONSTIPATION PROBLEMS
	Over the past week have you had constipation troubles that cause you difficulty moving your bowels?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Normal: No constipation
	1 = Slight: I have been constipated. I use extra effort to move my bowels. However, this problem does not disturb my activities or my being comfortable
	2 = Mild: Constipation causes me to have some troubles doing things or being comfortable
	3 = Moderate: Constipation causes me to have a lot of trouble doing things or being comfortable. However, it does not stop me from doing anything
	4 = Severe: I usually need physical help from someone else to empty my bowels

Variable ID:	MDSUPDRS_Q12
Variable:	Light headedness on standing
Definition:	1.12 LIGHT HEADEDNESS ON STANDING
	Over the past week, have you felt faint, dizzy or foggy when you stand up after sitting or lying down?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Normal: No dizzy or foggy feelings
	1 = Slight: Dizzy or foggy feelings occur. However, they do not cause me troubles doing things
	2 = Mild: Dizzy or foggy feelings cause me to hold on to something, but I do not need to sit or lie back down
	3 = Moderate: Dizzy or foggy feelings cause me to sit or lie down to avoid fainting or falling
	4 = Severe: Dizzy or foggy feelings cause me to fall or faint

Variable ID:	MDSUPDRS_Q13
Variable:	Fatigue
Definition:	1.13 FATIGUE
	Over the past week, have you usually felt fatigued? This feeling is not part of being sleepy or sad
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Normal: No fatigue
	1 = Slight: Fatigue occurs. However it does not cause me troubles doing things or being with people
	2 = Mild: Fatigue causes me some troubles doing things or being with people
	3 = Moderate: Fatigue causes me a lot of troubles doing things or being with people. However, it does not stop me from doing anything
	4 = Severe: Fatigue stops me from doing things or being with people
Variable ID:	NMSQ
Variable:	Sexual function/sweating
Definition:	Have you experienced any of the following in the last month?
Supporting Definition:	From the Non-motor symptoms questionnaire (NMSQ) by the International Parkinson's and Movement Disorders Society (IPMDS)
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	1 = Feeling less interested in sex or more interested in sex
	2 = Finding it difficult to have sex when you try
	3 = Excessive sweating

Motor Aspects of Experiences of Daily Living

Variable ID:	MDSUPDRS_Q21
Variable:	Speech
Definition:	2.1 SPEECH
	Over the past week, have you had problems with your speech?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Normal: Not at all (no problems)
	1 = Slight: My speech is soft, slurred or uneven, but it does not cause others to ask me to repeat myself
	2 = Mild: My speech causes people to ask me to occasionally repeat myself, but not everyday
	3 = Moderate: My speech is unclear enough that others ask me to repeat myself every day even though most of my speech is understood
	4 = Severe: Most or all of my speech cannot be understood
Variable ID:	MDSUPDRS_Q22
Variable:	Saliva and drooling
Definition:	2.2 SALIVA & DROOLING
	Over the past week, have you usually had too much saliva during when you are awake or when you sleep?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually

Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Normal: Not at all (no problems)
	1 = Slight: I have too much saliva, but do not drool
	2 = Mild: I have some drooling during sleep, but none when I am awake
	3 = Moderate: I have some drooling when I am awake, but I usually do not need tissues or a handkerchief
	4 = Severe: I have so much drooling that I regularly need to use tissues or a handkerchief to protect my clothes
Variable ID:	MDSUPDRS_Q23
Variable:	Chewing and swallowing
Definition:	2.3 CHEWING AND SWALLOWING
	Over the past week, have you usually had problems swallowing pills or eating meals? Do you need your pills cut or crushed or your meals to be made soft, chopped or blended to avoid choking?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Normal: No problems
	1 = Slight: I am aware of slowness in my chewing or increased effort at swallowing, but I do not choke or need to have my food specially prepared
	2 = Mild: I need to have my pills cut or my food specially prepared because of chewing or swallowing problems, but I have not choked over the past week
	3 = Moderate: I choked at least once in the past week
	4 = Severe: Because of chewing and swallowing problems, I need a feeding tube
Variable ID:	MDSUPDRS_Q24
Variable:	Eating tasks
Definition:	2.4 EATING TASKS
	Over the past week, have you usually had troubles handling your food and using eating utensils? For example, do you have trouble handing finger foods or using forks, knifes, spoons, chopsticks?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Normal: Not at all (no problems)
	1 = Slight: I am slow, but I do not need any help handling my food and have not had food spills while eating
	2 = Mild: I am slow with my eating and have occasional food spills. I may need help with a few tasks such as cutting meat
	3 = Moderate: I need help with many eating tasks but can manage some alone
	4 = Severe: I need help for most or all eating tasks
Variable ID:	MDSUPDRS_Q25
Variable:	Dressing
Definition:	2.5 DRESSING
	Over the past week, have you usually had problems dressing? For example, are you slow or do you need help with buttoning, using zippers, putting on or taking off your clothes or jewelry?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer

Response Options:	0 = Normal: Not at all (no problems)
	1 = Slight: I am slow but I do not need help
	2 = Mild: I am slow and need help for a few dressing tasks (buttons, bracelets)
	3 = Moderate: I need help for many dressing tasks
	4 = Severe: I need help for most or all dressing tasks
Variable ID:	MDSUPDRS_Q26
Variable:	Hygiene
Definition:	2.6 HYGIENE
	Over the past week, have you usually been slow or do you need help with washing, bathing, shaving, brushing teeth, combing your hair or with other personal hygiene?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Normal: Not at all (no problems)
	1 = Slight: I am slow but I do not need any help
	2 = Mild: I need someone else to help me with some hygiene tasks
	3 = Moderate: I need help for many hygiene tasks
	4 = Severe: I need help for most or all of my hygiene tasks
Variable ID:	MDSUPDRS_Q27
Variable:	Handwriting
Definition:	2.7 HANDWRITING
	Over the past week, have people usually had trouble reading your handwriting?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Normal: Not at all (no problems)
	1 = Slight: My writing is slow, clumsy or uneven, but all words are clear
	2 = Mild: Some words are unclear and difficult to read
	3 = Moderate: Many words are unclear and difficult to read
	4 = Severe: Most or all words cannot be read
Variable ID:	MDSUPDRS_Q28
Variable:	Doing hobbies and other activities
Definition:	2.8 DOING HOBBIES AND OTHER ACTIVITIES
	Over the past week, have you usually had trouble doing your hobbies or other things that you like to do?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Normal: Not at all (no problems)
	1 = Slight: I am a bit slow but do these activities easily
	2 = Mild: I have some difficult doing these activities
	3 = Moderate: I have major problems doing these activities, but still do most
	4 = Severe: I am unable to do most or all of these activities
Variable ID:	MDSUPDRS_Q29
Variable:	Turning in bed
Definition:	2.9 TURNING IN BED
	Over the past week, do you usually have trouble turning over in bed?
Supporting Definition:	N/A
Inclusion Criteria:	All patients

Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Normal: Not at all (no problems)
	1 = Slight: I have a bit of trouble turning, but I do not need any help
	2 = Mild: I have a lot of trouble turning and need occasional help from someone else
	3 = Moderate: To turn over I often need help from someone else
	4 = Severe: I am unable to turn over without help from someone else

Variable ID:	MDSUPDRS_Q30
Variable:	Tremor
Definition:	2.10 TREMOR
	Over the past week, have you usually had shaking or tremor?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Normal: Not at all. I have no shaking or tremor
	1 = Slight: Shaking or tremor occurs but does not cause problems with any activities
	2 = Mild: Shaking or tremor causes problems with only a few activities
	3 = Moderate: Shaking or tremor causes problems with many of my daily activities
	4 = Severe: Shaking or tremor causes problems with most or all activities

Variable ID:	MDSUPDRS_Q31
Variable:	Getting out of bed, a car, or a deep chair
Definition:	2.11 GETTING OUT OF BED, A CAR, OR A DEEP CHAIR
	Over the past week, have you usually had trouble getting out of bed, a car seat, or a deep chair?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Normal: Not at all (no problems)
	1 = Slight: I am slow or awkward, but usually can do it on my first try
	2 = Mild: I need more than one try to get up or need occasional help
	3 = Moderate: I sometimes need help to get up, but most times I can still do it on my own
	4 = Severe: I need help most or all of the time

Variable ID:	MDSUPDRS_Q32
Variable:	Walking and balance
Definition:	2.12 WALKING AND BALANCE
	Over the past week, have you usually had problems with balance and walking?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Normal: Not at all (no problems)
	1 = Slight: I am slightly slow or may drag a leg. I never use a walking aid
	2 = Mild: I occasionally use a walking aid, but I do not need any help from another person
	3 = Moderate: I usually use a walking aid (cane, walker) to walk safely without falling. However, I do not usually need the support of another person

4 = Severe: I usually use the support of another person to walk safely without falling

Variable ID:	MDSUPDRS_Q33
Variable:	Freezing
Definition:	2.13 FREEZING
	Over the past week, on your usual day when walking, do you suddenly stop of freeze as if your feet are stuck to the floor?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Normal: Not at all (no problems)
	1 = Slight: I briefly freeze but I can easily start walking again. I do not need help from someone else or a walking aid (cane or walker) because of freezing
	2 = Mild: I freeze and have trouble starting to walk again, but I do not need someone's help or a walking aid (cane or walker) because of freezing
	3 = Moderate: When I freeze I have a lot of trouble starting to walk again and, because of freezing, I sometimes need to use a walking aid or need someone else's help
	4 = Severe: Because of freezing, most or all of the time, I need to use a walking aid or someone's help

Overall Health Status

Variable ID:	WORK
Variable:	Ability to work
Definition:	Is your Parkinson's Disease limiting your ability to work?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = No
	1 = Yes

Variable ID:	ADMIS
Variable:	Hospital admissions
Definition:	Have you been admitted to the hospital in the last 12 months?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = No
	1 = Yes

Variable ID:	ADMISNO
Variable:	Number of admissions
Definition:	How many times have you been admitted to a hospital in the last 12 months?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
	If answered 'yes' to admissions (ADMIS)
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Numerical value
Response Options:	Number of admissions

Variable ID:	ADMISPD
Variable:	Admissions due to Parkinson's

Definition:	How many of these admissions were related to your Parkinson's Disease?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
	If answered 'yes' to admissions (ADMIS)
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Numerical value
Response Options:	Number of admissions related to Parkinson's Disease

Variable ID:	PDQ8_Q01
Variable:	Question 1 of PDQ-8
Definition:	Due to having Parkinson's disease, how often during the last month have you…
	1. Had difficulty getting around in public?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Never
	1 = Occasionally
	2 = Sometimes
	3 = Often
	4 = Always or cannot do at all

Variable ID:	PDQ8_Q02
Variable:	Question 2 of PDQ-8
Definition:	2. Had difficulty dressing yourself?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Never
	1 = Occasionally
	2 = Sometimes
	3 = Often
	4 = Always or cannot do at all

Variable ID:	PDQ8_Q03
Variable:	Question 3 of PDQ-8
Definition:	3. Felt depressed?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Never
	1 = Occasionally
	2 = Sometimes
	3 = Often
	4 = Always or cannot do at all

Variable ID:	PDQ8_Q04
Variable:	Question 4 of PDQ-8
Definition:	4. Had problems with your close personal relationships?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer

Response Options:	0 = Never
	1 = Occasionally
	2 = Sometimes
	3 = Often
	4 = Always or cannot do at all

Variable ID:	PDQ8_Q05
Variable:	Question 5 of PDQ-8
Definition:	5. Had problems with your concentration, for example when reading or watching TV?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Never
	1 = Occasionally
	2 = Sometimes
	3 = Often
	4 = Always or cannot do at all

Variable ID:	PDQ8_Q06
Variable:	Question 6 of PDQ-8
Definition:	6. Felt unable to communicate with people properly?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Never
	1 = Occasionally
	2 = Sometimes
	3 = Often
	4 = Always or cannot do at all

Variable ID:	PDQ8_Q07
Variable:	Question 7 of PDQ-8
Definition:	7. Had painful muscle cramps or spasms?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Never
	1 = Occasionally
	2 = Sometimes
	3 = Often
	4 = Always or cannot do at all

Variable ID:	PDQ8_Q08
Variable:	Question 8 of PDQ-8
Definition:	8. Felt embarrassed in public due to having Parkinson's disease?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = Never
	1 = Occasionally
	2 = Sometimes

3 = Often

4 = Always or cannot do at all

Variable ID:	FALLS
Variable:	Falls
Definition:	Did you fall last year?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = No
	1 = Yes

Variable ID:	BONE
Variable:	Bone fracture
Definition:	Did you suffer a bone fracture as a result?
Supporting Definition:	N/A
Inclusion Criteria:	All patients
	If answered 'yes' to falls (FALLS)
Timing:	Baseline and annually
Data Source:	Patient-reported
Type:	Single answer
Response Options:	0 = No
	1 = Yes

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Reference Guide Revisions

Reference Guide Version	Location within Reference Guide	Content Change
2.2.1	Contact Information	Removed inactive email address: ichomteam@ichom.org

www.ichom.org