

Schedule of Activities- Longitudinal

Schedule of Activities- Parkinson’s Disease (PD) Participants

	Freq. (months)	Reg.	*0-30 days from reg.	91- 120 days from reg.	181- 210 days from reg.	271- 300 days from reg.	361- 390 days from reg.	451- 480 days since reg.	541- 570 days since reg.	631- 660 days since reg.	721- 750 days since reg.	811- 840 days since reg.	901- 930 days since reg.	991- 1020 days since reg.	1081 - 1110 days since reg.	1171 - 1200 days since reg.	1261 - 1290 days since reg.	1791 - 1820 days since reg.	Rolling Until Complete
Activities Months (~30 days)		0	0	3	6	9	12	15	18	21	24	27	30	33	36	39	42	60	
FI Account (Registration)	Once	X																	
Informed Consent	Once	X																	
Privacy Agreement	Once	X																	
About You (Profile)	12	X					X (SM)				X (SM)				X (SM)				X
Return Visit Questionnaire (PD)	3			X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Tell us how you are completing this study visit	3		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Clinical Global Impression of Change (PD) (CGIC)	3			X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
What’s Bothering You? (PD Patient Reported Outcome of Problem (PD-PROP; Shoulson))	3		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Your Daily Living (PDQ-8)	3		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Your Non-Movement Experiences NMS Quest (PD)	3		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Brief Motor Screen	3		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Your Mood (GDS)	12		X	X				X				X				X			
Your Sleep Habits (REM Sleep Behavior Disorder Single-Question Screen (RBD1Q))	12		X		X				X				X				X		
Your Cognition and Daily Activities (PDAQ-15) <sup>a</sup>	6		X		X		X		X		X		X		X		X		
Your Movement Experiences (MDS-UPDRS)	6		X	X		X		X		X		X		X		X			
Your Physical Activities (PASE)	12		X	X				X				X				X			
Your Physical Experiences (EQ-5D-5L)	6		X	X		X		X		X		X		X		X		X	
Side of Onset	Once		X																X
Your Medications (PD) (v3)	3		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
Your Family Neurological History	12		X	X (SM)				X (SM)				X (SM)				X (SM)			

Schedule of Activities- Longitudinal

Your Health History	Once		X																	X
Your Current Health	12		X	X (SM)				X (SM)				X (SM)				X (SM)				
Your Acute Medical Conditions	12			X				X				X				X				X
Your Medication History	Once		X																	X
Handedness Questionnaire (Edinburgh Handedness short form)	Once		X																	X

\*Prior to 9/5/2019, participants had 90 days to complete all questionnaires within a study visit.

<sup>a</sup>Your Cognition and Daily Activities (PDAQ-15) data and dictionary were recoded 6/1/2020 to reflect the current literature in which LOWER scores mean WORSE cognitive function

SM: Surveys will be presented in full versions unless noted that survey will be presented in summary mode

Schedule of Activities- Longitudinal

Schedule of Activities- NON-PD Participants

	Freq. (months)	Reg.	*0-30 days from reg.	91- 120 days from reg.	181- 210 days from reg.	271- 300 days from reg.	361- 390 days from reg.	451- 480 days since reg.	541- 570 days since reg.	631- 660 days since reg.	721- 750 days since reg.	811- 840 days since reg.	901- 930 days since reg.	991- 1020 days since reg.	1081 - 1110 days since reg.	1171 - 1200 days since reg.	1261 - 1290 days since reg.		1791 - 1820 days since reg.	Rolling Until Complete
Activities Months (~30 days)		0	0	3	6	9	12	15	18	21	24	27	30	33	36	39	42		60	
FI Account (Registration)	once	X																		
Informed Consent	once	X																		
Privacy Agreement	once	X																		
About You (Profile)	12	X					X (SM)				X (SM)				X (SM)					X
Return Visit Questionnaire (Non-PD)	3			X	X	X	X	X	X	X	X	X	X	X	X	X	X		X	
Clinical Global Impression of Change (Non-PD) (CGIC)	3			X	X	X	X	X	X	X	X	X	X	X	X	X	X		X	
Brief Motor Screen	3		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X		X	
Your Non-Movement Experiences NMS Quest (Non-PD)	3		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X		X	
Your Mood (GDS)	12		X	X				X				X				X				
Your Sleep Habits (REM Sleep Behavior Disorder Single-Question Screen (RBD1Q)	12		X		X				X				X				X			
Your Cognition and Daily Activities (PDAQ-15)	6		X		X		X		X		X		X		X		X			
Your Physical Activities (PASE)	12		X	X				X				X				X				
Your Physical Experiences (EQ-5D-5L)	6		X	X		X		X		X		X		X		X			X	
Your Family Neurological History	12		X	X (SM)				X (SM)				X (SM)				X (SM)				
Your Health History	Once		X																	X
Your Current Health	12		X	X (SM)				X (SM)				X (SM)				X (SM)				
Your Acute Medical Conditions	12			X				X				X				X				X
Your Medications (Non-PD)	3		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X		X	
Handedness Questionnaire (Edinburgh Handedness short form)	Once		X																	X

\*Prior to 9/5/2019, participants had 90 days to complete all questionnaires within a study visit.  
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Schedule of Activities- Longitudinal

Cross-sectional health and disease questionnaires

Questionnaire name	Cohort
Environmental Exposure Questionnaires	All
Patient Therapeutic Preferences Questionnaire	PD
Impact and Communication on OFF Periods	PD
The Financial and Social Impact of Parkinson’s Disease Survey	PD
Understanding OFF and ON in Parkinson’s Patients	PD
Understanding Fatigue in Parkinson’s Patients	PD
Understanding Psychosis and its Burden on Caregivers	Non-PD
The role of stress in Parkinson’s disease	PD
The Role of Stress in Parkinson’s disease (Control)	Non-PD
Compensation strategies to improve walking in persons with PD	PD
Cannabis Use in PD	PD
Experiences with Sensory Misperceptions	All
COVID-19 Experience in the PD Community	All
Repetitive Head Impact	All
Assessing discrimination in healthcare, quality of life and PD symptom burden	All
COVID-19 Experience in the PD Community – Part 2	All
Medication Deprescribing and Clinical Research Study Participation	All
Care Partner Experiences	Non-PD
Experiences of Women Living with PD – Female Health and Home Life	PD
Attitudes and Beliefs Regarding Research and Genetic Testing for Parkinson’s disease	All
Mood disorders and Parkinson’s disease	All
Experiences of Women Living with PD – Pre, Peri, and Post Menopause	PD
Impact of Thinking, Mood, and Motor Symptoms	PD

Deep Brain Stimulation (DBS) in Early Stage Parkinson’s disease	All
Understanding Parkinson’s Disease, Neurodevelopment and Autism Spectrum Disorder (ASD)	All
Uncertainty in Parkinson’s Disease	PD
The Financial and Social Impact of Parkinson’s Disease and Parkinson’s Related Disorders	All
Experiences of Women Living with PD – Fertility, Pregnancy, and Childbirth	PD
Quality of Life and Symptoms in People with PD after DBS	All