SUPPLEMENTAL MATERIALS: APPENDIX 2

The MDS-UPDRS Appendix Committee was charged with the development of recommendations on the use of additional scales for the assessment of behaviors captured with screening questions on the MDS-UPDRS. These scales are intended to considered by researchers and clinicians who wish to assess a given behavior in more detail than provided by the MDS-UPDRS.

This committee has worked with two strategies, and will update these tables as new information is available. In Table A, data are derived from published reports written by the Task Force on PD Rating Scales. In Table B, the Appendix Committee has made recommendations, but will defer to final publications by the Task Force on PD Rating Scales when these reports are completed. In both assessments, uniform definitions have been applied:

R: Recommended: A scale is considered Recommended if it has been applied to PD populations, there are data on its use in studies beyond the group that developed the scale, and it has been studied clinimetrically and found valid, reliable and sensitive to change.

S: Suggested: A scale is considered Suggested if it has been applied to PD populations, but only one of the other criteria applies.

L: Listed: A scale is Listed if it meets only one of the three criteria defined for recommended scales.

These qualifications may pertain to specific properties of the scale, such as screening for the presence or absence of the behavior and measuring severity and change in severity during treatment.

TABLE A:
SCALE EVALUATIONS FROM THE REPORTS BY THE MDS TASK FORCE ON PD RATING SCALES.

Domain	Scales selection (criteria)	Temporal Window	Scales	Goal: Diagnostic Screening or Rating Severity	Grading	Comments
DEPRESSION	Scales analyzed have either been used previously to assess depression in PD in more than one study, or, based on literature review and expert evaluation, have potential utility in PD based on their content, their widespread use, and clinimetric evidence from studies in depressed patients without PD. This latter criterion was just applicable to CES-D and CSDD. Only depression-specific scales were considered. Multi-dimensional scales were excluded.	Up to June 2005	HAM-D	Screening	R	Based on Shragg et al 2007 (1) with input from the MDS-UPDRS Appendix Committee (C. Sampaio, chair). The task force considered that it was not appropriate to invest efforts in developing a new scale of PD depression rather one of the recommended should be systematically studied and characterized clinimetrically.
				Severity	R	
			MADRS	Screening	S	
				Severity	R	
			BDI	Screening	R	
				Severity	S	
			HADS	Screening	S	
				Severity	L	
			Zung	Screening	S	
				Severity	S	
			GDS	Screening	R	
				Severity	L	
			UPDRS I	Screening	S	
				Severity	L	
			CES-D	Screening	L	
				Severity	L	
			CSDD	Screening	L	
				Severity	L	

Beck Depression Inventory (BDI), Hamilton Depression Scale (Ham-D), Hospital Anxiety and Depression Scale (HADS), Zung Self-Rating Depression Scale (SDS), Geriatric Depression Scale (GDS), Montgomery-Asberg Depression Rating Scale (MADRS), Unified Parkinson's Disease Rating Scale (UPDRS) part I, Cornell Scale for the Assessment of Depression in Dementia (CSDD), and Center for Epidemiologic Studies Depression Scale (CES-D).

Domain	Scales selection (criteria)	Temporal Window	Scales	Goal: Diagnostic Screening or Rating Severity	Grading	Comments
PSYCHOSIS	Scales analyzed were used in published, peer-reviewed PD psychosis studies.	Up to Set 2005	PPRS	Not specified	S	Based on Fernandez et al 2008. (2) The task force considered that none of the scales evaluated captures the full phenomenology of PD psychosis and therefore recommends the investment in the development of a dedicated scale.
			PPQ	Not specified	S	
			RHI	Not specified	L	
			BHQ	Not specified	L	
			NPI	Not specified	R	
			BEHAVE-AD	Not specified	S	
			BPRS	Not specified	R	
			PNSS	Not specified	R	
			SAPS	Not specified	R	
			NOSIE	Not specified	L	
			CGIS	Not specified	S	
			UPDRS Part I	Not specified	L	

Parkinson Psychosis Rating Scale (PPRS), Parkinson Psychosis Questionnaire (PPQ),) Rush Hallucination Inventory(RHI),Baylor Hallucinations Questionnaire (BHQ),Neuropsychiatric Inventory (NPI), Behavioral Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD),) Brief Psychiatric Rating Scale (BPRS),Positive and Negative Syndrome Scale (PANSS),Schedule for Assessment of Positive Symptoms (SAPS), Nurses' Observation Scale for Inpatient Evaluation (NOSIE-30), Clinical Global Impression Scale (CGIS),Unified Parkinson Disease Rating Scale (UPDRS) Part I,

Domain	Scales selection (criteria)	Temporal Window	Scales	Goal: Diagnostic Screening or Rating Severity	Grading	Comments
ANXIOUS MOOD	Scales analyzed have been designed to assess anxiety and that have been either validated or used in studies with PD patients. Multidimensional scales were excluded. An exception was made for the anxiety subscale of the Neuropsychiatric Inventory (NPI), because of the frequency with which this instrument is used to assess psychiatric symptoms in PD. Although obsessive compulsive disorder is considered an anxiety disorder in the DSM classification (but not in	Up to Feb 2007	BAI	Screening *Only for panic attacks*	S	Based on Leentjens et al 2008. (3). The task force considered it is not clear if efforts to develop a new scale for Anxiety in PD will be cost-effective. They recommended further investment in characterizing and validating the available scales.
				Severity	S	
			HADS	Screening	S	
				Severity	L	
			Zung SAS	Screening	S	
				Severity	S	
			Zung ASI	Screening	S	
				Severity	S	
			STAI	Screening	S	
				Severity	S	
			HARS	Screening	S	
				Severity	S	
			NPI Item 5	Screening	S	
				Severity	S	

Beck Anxiety Inventory (BAI) , the Hospital Anxiety and Depression Scale (HADS) , the Zung Self-rating Anxiety Scale (SAS) and Anxiety Status Inventory (ASI) , the Spielberger State Trait Anxiety Inventory (STAI) , and the Hamilton Anxiety Rating Scale (HARS), NPI

Domain	Scales selection (criteria)	Temporal Window	Scales	Goal: Diagnostic Screening or Rating Severity	Grading	Comments
APATY/ ANHEDONIA	Scales analyzed have been designed to assess apathy or anhedonia and that have been either validated or used in studies with PD patients. Multidimensional scales were excluded. Scales assessing momentary mood states, such as the Profile of Moods States Questionnaire (POMS) were also excluded. Because of its special status in the assessment of PD patients, as well as its wide use, an exception was made for item 4 (motivation) of part 1 of the Unified Parkinson's Disease Rating Scale (UPDRS)	Up to Feb 2007	AES	Screening	S	Based on Leentjens et al 2008 (4). The task force considered there is need to better characterize the definitions of apathy and anhedonia before engaging in further validation studies for the existing scales that are considered necessary.
				Severity	S	
			AS	Screening	R	
				Severity	R	
			AI	Screening	L	
				Severity	L	
			LARS	Screening	S	
				Severity	L	
			UPDRS Item 4	Screening	R	
				Severity	L	
			NPI Item 7	Screening	S	
				Severity	L	
			SHAPS	Screening	S	
				Severity	S	
			Chapman	Screening	L	
				Severity	L	

Apathy Evaluation Scale (AES), the Apathy Scale (AS), the Apathy Inventory (AI), and the Lille Apathy Rating Scale (LARS). In addition, item 4 (motivation/initiative) of the Unified Parkinson's Disease Rating Scale (UPDRS), and item 7 (apathy) of the Neuropsychiatric Inventory (NPI) were included. Anhedonia scales identified for review were the Snaith-Hamilton Pleasure Scale (SHAPS) and the Chapman scales for physical and social anhedonia.

Domain	Scales selection (criteria)	Temporal Window		Scales	Goal: Diagnostic Screening or Rating Severity	Grading	Comments
DYSAUTONOMIA Upper and lower gastrointestinal dysautonomia symptoms (GIDS)	Scales analyzed were used in the assessment of sialorrhea, dysphagia and constipation. Scales previously used as outcome measures in studies of patients with PD were selected for evaluation. If no such scales were identified, scales used in other populations were selected for evaluation	Up to June 2007?	Sialorrhea	DSFS-S	Not specified	S	Based on Evatt et al 2008. (5).
				DRL	Not specified	S	
				SCS-PD-S	Not Specified	S	
			Dysphagia	SDQ	Not specified	S	
				SWAL QOL-S	Not specified	S	
			Constipation	No scales identified ROME III module			
			Generic scales	SCOPA AUT	Screening	R	
					Follow-up	L	
				NMS	Screening	R	
					Follow-up	L	
				NMSS	Screening	S	
					Follow-up	L	
Drooling Severity and Frequency Scale (DSFS),Drooling Rating Scale (DRS), Sialorrhea Clinical Scale for Parkinson's disease (SCS-PD),Swallowing Disturbance Questionnaire (SDQ),Generic Scale for Dysphagia-related Outcomes (Quality of Life) – SWALQOL, The Scales for Outcomes in Parkinson's disease – Autonomic, or SCOPAAUT,Nonmotor symptoms questionnaire for Parkinson's disease (NMSQuest), Nonmotor Symptoms Scale (NMSS)							

B: RECOMMENDATIONS FROM THE APPENDIX COMMITTEE OF THE MDS-UPDRS. (SUBJECT TO MODIFICATION WHEN FULL EVALUATIONS BY MDS TASK FORCE ON PD RATING SCALES ARE COMPLETE) (7).

Domain	Scales selection (criteria)	Temporal Window	Scales	Goal: Diagnostic Screening or Rating Severity	Grading	Comments
PAIN	Scales considered in the EFNS systematic review on the assessment of neuropathic pain were considered. Pain associated with PD is considered central in origin what makes it a type of neuropathic pain. However it is also admitted that there are cases where peripheral stimuli are the pain trigger, this pain is probably nociceptive. Pain in PD is not fully understood but for the purpose of this chart we consider that primary pain associated with PD is neuropathic.	Up to June 2007	VAS	Screening	R	Based on Cruccu et al 2006. (6). Grading was inferred by the MDS-UPDRS Appendix committee chair from the quoted paper plus the specific references on pain and PD retrieved from Pubmed A full report from the task force is still in preparation but it seems import to invest in characterizing the pain phenomenology in PD before taking the decision about developing a specific scale or not.
				Severity	R	
			NRS	Screening	S	
				Severity	S	
			VRS	Screening	S	
				Severity	S	
			11-likert	Screening	S	
				Severity	S	
			PRS	Screening	NA	
				Severity	L	
			GPS	Screening	L	
				Severity	L	
			MPQ	Screening	L	
				Severity	L	
			SF-MPQ	Screening	R	
				Severity	S	
			SSS	Screening	L	
				Severity	L	
			NPS	Screening	L	
				Severity	L	
			NPSI	Screening	S	
				Severity	S	
			CGI	Screening	NA	
				Severity	L	

QST- quantitative sensory testing. It is not a scale (thus it is not mentioned in the chart) but rather a laboratory measurement. It is not considered appropriate for screening but it can be useful for quantification of treatment effects. It is the method most frequently used in papers dedicated to pain in PD. The Leeds assessment of neuropathic symptoms and signs (LANSS scale) and Neuropathic Pain Questionnaire (NPQ) have been developed to differentiate neuropathic from nociceptive pain patients, rather than tools for quantitative assessment. They are not considered in the chart. The Brief Pain Inventory (BPI) was developed to measure pain in cancer patients. It was not analyzed in Cruccu et al paper but it has been used once in a study of pain in PD.
Visual analog (VAS), numerical rating (NRS), verbal rating (VRS) scale, 11-likert scale, Gracely Pain Scale (GPS), McGill Pain Questionnaire (MPQ), short-form. McGill Pain Questionnaire (SF-MPQ), the Symptom Score Scale (SSS),Neuropathic Pain Scale (NPS),Neuropathic Pain Symptom Inventory (NPSI), Pain relief scale (PRS), clinical global impression (CGI).

Domain	Scales selection (criteria)	Temporal Window	Scales	Goal: Diagnostic Screening or Rating Severity	Grading	Comments
COGNITION (NOT DEMENTIA)	Relative to age-matched normal controls, most non-demented patients with PD are impaired in several cognitive tasks. Poor performance even occurs in early stages. Only scales specifically develop for cognitive impairment in PD	Up to April 2004	MMP	Not specified	L	Based on the appendices committee original report.
			SCOPA-Cog	Not specified	S	
			BAECD	Not specified	S	
			FAB	Not specified	L	

Mini Mental Parkinson (MMP), SCales for Outcomes of PArkinson's disease–cognition (SCOPA-Cog), Brief assessment of executive control dysfunction (BAECD), Frontal battery dysfunction (FAB).

Domain	Scales selection (criteria)	Temporal Window	Scales	Goal: Diagnostic Screening or Rating Severity	Grading	Comments
Parkinson Disease Dementia	Scales analyzed were used in published, peer-reviewed PD Dementia studies.	Up to April 2004	MMSE	Not specified	L	Based on the appendices committee original report and one the MDS PDD task force 2nd paper, in press.
			ADAS-Cog	Not specified	S	
			MDRS	Not specified	R	
			NPI	Not specified	L	

Mini Mental Score (MMSE), The Alzheimer's Disease Assessment Scale-cognitive subscale (ADAS-Cog), The Mattis' Dementia Ratin Neuropsychiatric Inventory (NPI),

Domain	Scales selection (criteria)	Temporal Window	Scales	Goal: Diagnostic Screening or Rating Severity	Grading	Comments
FATIGUE	Scales analyzed were used in published, peer-reviewed PD studies.	Up to March 2008	FSS	Not specified	R	Based on the appendices committee original report and a new search of Pubmed made in March 2008. Analysis was only preliminary, made by CS
			MFI	Not specified	S	
			PFS	Not specified	R	

Fatigue severity scale (FSS), Multidimensional Fatigue Inventory (MFI), Parkinson Fatigue Scale (PFS)

Domain	Scales selection (criteria)	Temporal Window	Scales	Goal: Diagnostic Screening or Rating Severity	Grading	Comments
NOCTURNAL SLEEP	Scales analyzed have been designed to assess insomnia and/or quality of sleep in PD studies.	Up to March 2008	PSQI	Screening	R	Based on the appendices committee original report and a new search of Pubmed made in March 2008.
				Severity	R	
			SCOPA Sleep	Screening	S	
				Severity	S	
			SDQ	Screening	L	
				Severity	NA	
			NSFSS	Screening	L	
				Severity	NA	
			PDSS	Screening	R	
				Severity	R	
			MPDSS	Screening	L	
				Severity	L	

The Pittsburgh Sleep Quality Index (PSQI), SCOPA-SLEEP nighttime sleep sub-scale (SCOPA-Sleep), Sleep Disorders Questionnaire (SDQ) National Sleep Foundation sleep survey (NSFSS), Parkinson's disease sleep scale (PDSS), Modified Parkinson's disease sleep scale (MPDSS).

Domain	Scales selection (criteria)	Temporal Window	Scales	Goal: Diagnostic Screening or Rating Severity	Grading	Comments
DAYTIME SLEEPINESS	Scales analyzed have been designed to assess daytime sleepiness or "sleep attacks" in PD studies.	Up to March 2008	ESS	Screening	R	Based on the appendices committee original report and a new search of Pubmed made in March 2008.
				Severity	R	
			SCOPA Sleep Day	Screening	S	
				Severity	S	
			PDSS Item 15	Screening	L	
				Severity	L	
			SSS	Screening	L	
				Severity	L	
			KSS	Screening	L	
				Severity	L	

Epworth Sleepiness Scale (ESS), SCOPA-SLEEP daytime sleepiness sub-scale, Parkinson's disease sleep scale, The Stanford sleepiness scale (SSS) The Karolinska sleepiness scale (KSS)

Domain	Scales selection (criteria)	Temporal Window	Scales	Goal: Diagnostic Screening or Rating Severity	Grading	Comments
ORTHOSTATIC HYPOTENSION	Scales analyzed included a number of generic scales assessing autonomic related symptoms, including OH. Some of these scales are specific for PD. There are also generic autonomic scales with OH subdomains not specific for PD, but used in studies of PD. Additionally, there are scales developed to evaluate symptoms associated with orthostatic intolerance (not exclusively related to OH, but they have not been applied to PD cohorts. (see text)	Up to March 2008	SCOPA-AUT	Screening	L	Based on the MDS-UPDRS Appendix Committee report and a new search of Pubmed made in March 2008.
				Severity	L	
			NMS Quest	Screening	L	
				Severity	L	
			NMSS	Screening	L	
				Severity	L	
			COMPASS	Screening	L	
				Severity	L	
			OGS	Screening	L	
				Severity	L	
			OHSA	Screening	L	
				Severity	L	

SCOPA-AUT: Autonomic Subscale of the SCOPA program; NMSQuest: Non-Motor Symptom Questionnaire; NMSS: Non-Motor Symptoms Scale; COMPASS: Composite Autonomic Symptom Scale; OGS: Orthostatic Grading Scale; OHSA: Orthostatic Hypotension Symptoms Assessment.

Domain	Scales selection (criteria)	Temporal Window	Scales	Goal: Diagnostic Screening or Rating Severity	Grading	Comments
ERECTILE DYSFUNCTION	See text.	Up to March 2008	IIEF	Not specified	S	Based on the MDS-UPDRS Appendix Committee report and a new search of Pubmed made in March 2008.
			IIEF-5 SHIM	Not specified	S	

IIEF: International Index of Erectile Function; IIEF-5 or SHIM: International Index of Erectile Function 5 item (short version), also known as Sexual Health Inventory for Men.

Domain	Scales selection (criteria)	Temporal Window	Scales	Goal: Diagnostic Screening or Rating Severity	Grading	Comments
URINARY TRACT SYMPTOMS	Scales analyzed included standard urinary symptom scoring methods, but for men, these scales do not differentiate symptoms due to neurological dysfunction from benign prostatic hypertrophy. Other scales deal with overall pelvic organ dysfunction. (see text).	Up to March 2008	AUASI (men)	Screening	S	Based on the MDS-UPDRS Appendix Committee report and a new search of Pubmed made in March 2008.
				Severity	L	
			UDI-6 (women)	Screening	S	
				Severity	L	
			Sakakibara	Screening	L	
				Severity	L	
			IPSS	Screening	S	
				Severity	L	

AUASI: American Urological Association Symptom Index; UDS-6: Urogenital Distress Inventory-6; IPSS: International Prostate Symptoms Score.

References for Supplemental Material Appendix 2:

1. Schrag A, Barone P, Brown RG, Leentjens AF, McDonald WM, Starkstein S, Weintraub D, Poewe W, Rascol O, Sampaio C, Stebbins GT, Goetz CG. Depression rating scales in Parkinson's disease: critique and recommendations. *Mov Disord*. 2007;22(8):1077-92.
2. Fernandez HH, Aarsland D, Fénelon G, Friedman JH, Marsh L, Tröster AI, Poewe W, Rascol O, Sampaio C, Stebbins GT, Goetz CG. Scales to assess psychosis in Parkinson's disease: Critique and recommendations. *Mov Disord.* 2008;23:484-500.
3. Leentjens AFG, Dujardin K, Marsh L, Martinez-Martin P, Richard IH, Starkstein SE, Weintraub D, Sampaio C, Poewe W, Rascol O, Stebbins GT, Goetz CG. Anxiety rating scales in Parkinson's disease: critique and recommendations. *Mov Disord* 2008; (in press).
4. Leentjens AFG, Dujardin K, Marsh L, Martinez-Martin P, Richard IH, Starkstein SE, Weintraub D, Sampaio C, Poewe W, Rascol O, Stebbins GT, Goetz CG. Apathy and anhedonia rating scales in Parkinson's disease: critique and recommendations. *Mov Disord* 2008; (in press).
5. Evatt ML, Chaudhuri KR, Chou KL, Cubo E, Hinson VK, Kompoliti K, Yang C, Poewe W, Rascol O, Sampaio S, Stebbins GT, Goetz CG. Dysautonomia Rating Scales in Parkinson’s Disease: Sialorrhea, Dysphagia, and Constipation: Critique and recommendations to Movement Disorders Task Force on Rating Scales for Parkinson’s disease. *Mov Disord* 2008; (in press).

6. G. Cruccu, P. Anand, N. Attal, L. Garcia-Larrea, M. Haanpää, E. Jørum, J. Serra, T.S. Jensena. Guidelines on Assessment of Neuropathic Pain and Response to Treatment (pp. 234-247). In: *European Handbook of Neurological Management official EFNS guidelines,* Hughes R, Brainin M, Gilhus NE (editors), 1st Edition, Backwell P LTD.,Oxford UK 2006.
7. Goetz CG, Sampaio C. Assessment of non-motor features of PD: Scales and Rating Tools. IN: *Non-motor and non-dopaminergic features of Parkinson's disease,* eds. Olanow CW, Stocchi F, Lang AE. Oxford UK, Blackwell, 2008 (in press).