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	Temporal	Scales	Goal:	Grading	Comments
2011411	selection	Window	Searcs	Diagnostic	Oracing	
	(criteria)			Screening		
	(=======			or Rating		
				Severity		
	in ve		HAM-D	Screening	R	Based on Shragg et al 2007 (1)
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	n, ha			Severity	R	with input from
	on in lation and This		MADRS	Screening	S	the MDS- UPDRS
	ressic evalu use, a PD. ssion-	Scales were considered. Multi-dimensional scales were excluded. Up to June 2005		Severity	R	Appendix
	dep pert read thout epres		BDI	Screening	R	Committee (C. Sampaio, chair).
	ssess d exi despi s wii nly d			Severity	S	The task force considered that it
Z	to a w an w an ir wid trient then to Or. Or. or were states the states of the states o	Up to June 2005	HADS	Screening	S	
01	ously revie the ed pa ed pa cales			Severity	L	was not appropriate to
SS	revicure intent ntent oresse und C	ne	Zung	Screening	S	invest efforts in
RE	sed priteral iteral iteral room room room room room room room roo	Ju o		Severity	S	developing a new scale of PD
DEPRESSION	on 1 on 1 the ites in ites in CES	p tc	GDS	Screening	R	depression rather one of the
Ω	er be vased ed or stud stud	Ū		Severity	L	recommended
	eith or, b bas from from dicat		UPDRS	Screening	S	should be systematically
	have udy, n PD nn PD nnce t app		I	Severity	L	studied and characterized
	zed ne st lity i evide s jus cons		CES-D	Screening	L	characterized clinimetrically.
	analy nan o al uti tric e n wa vere			Severity	L	
	Scales analyzed have eithe more than one study, or, b potential utility in PD base clinimetric evidence from criterion was just applicab scales were considered. M		CSDD	Screening	L	
	Sc mc Clii			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	Temporal Window	Scales	Goal:	Grading	Comments
	selection (criteria)	WIIIdow		Diagnostic Screening		
	(Criteria)			or Rating		
				Severity		
			PPRS	Not	S	Based on
				specified		Fernandez et al 2008. (2)
			PPQ	Not	S	The task force
				specified		considered that
			RHI	Not	L	none of the scales evaluated
				specified		captures the full phenomenology
			BHQ	Not	L	of PD psychosis
	ies.			specified	_	and therefore recommends
	stud		NPI	Not	R	the investment in the
	osis		DELLAND	specified	C	development of
SIS	sych	00	BEHAVE- AD	Not	S	a dedicated scale.
PSYCHOSIS	PD 1	Up to Set 2005	AD	specified		
\ C.	pəmə	S S	BPRS	Not	R	
PSY	-revi	Γ	Brits	specified	1	
	peer		PNSS	Not	R	
	shed,			specified		
	ublis		SAPS	Not	R	
	l in p			specified		
	Scales analyzed were used in published, peer-reviewed PD psychosis studies.		NOSIE	Not	L	
	were			specified		
	/zed		CGIS	Not	S	
	anal			specified		
	ales		UPDRS	Not	L	
		ne) n-uliu n	Part I	specified		

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
	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		BAI	Screening Only for panic attacks Severity	S	Based on Leentjens et al 2008. (3).
	and t uts. was / (NF asse; pulsi pulsi ation		HADS	Screening	S	considered it is not clear if
	Scales analyzed have been designed to assess anxiety and the been either validated or used in studies with PD patients. Multidimensional scales were excluded. An exception was not the anxiety subscale of the Neuropsychiatric Inventory (NPI) of the frequency with which this instrument is used to assess psychiatric symptoms in PD. Although obsessive compulsive is considered an anxiety disorder in the DSM classification (1)			Severity	L	efforts to
ANXIOUS MOOD	ss ans PD 1 exce Exce Inve is us is us sssive	07	Zung	Screening	S	develop a new scale for
MC MC	asses with An iatric nent obse	2007	SAS	Severity	S	Anxiety in PD will be cost-
	d to idies anded sych sych istruiough	eb	Zung	Screening	S	effective. They
10	signe n stu excl urop nis in Althc	to Feb	ASI	Severity	S	recommended further
🔀	n des sed i were e Ne ich th PD. /	Up t	STAI	Screening	S	investment in characterizing
 A	or u or u ales v of the sin I sin I sin I ety c	n n		Severity	S	and validating
	have lated al scale cale with with stom		HARS	Screening	S	the available scales.
	rzed valid sions sions subsect cency symp			Severity	S	
	analy ther men iety requi		NPI	Screening	S	
	Scales analyzed I been either valid Multidimensiona the anxiety subso of the frequency psychiatric symp is considered an		Item 5	Severity	S	
	Sc. bee Mt. the of of is c.					

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
	were e use, tting		AES	Screening	S	Based on Leentjens et al
nd that have been either as were excluded. Scales ex Questionnaire (POMS) patients, as well as its widded Parkinson's Disease Ra	er ules MS) v wide se Rati			Severity	S	2008 (4).
	en eith ed. Sc: re (PO I as its Disea		AS	Screening	R	The task force considered there is need to
	ave be exclud- ionnai as wel nson's			Severity	R	better characterize the
	were of Quest itents,		AI	Screening	L	definitions of apathy and
	nia anc scales States PD pa Jniffied			Severity	L	anhedonia before engaging
DON	nhedor Isional Moods nent of of the U	Up to Feb 2007	LARS	Screening	S	in further validation studies for the
	ny or a idimer ille of] ssessn			Severity	L	existing scales that are
APATY/ ANHEDONIA	ss apatl s. Mult he Proi n the a on) of j		UPDRS	Screening	R	considered necessary.
\TY	o asses vatients ch as th status i	ָב ב	Item 4	Severity	L	
AP/	gned to h PD p tes, such pecial secial secia		NPI	Screening	S	
	en desi ies wit ood sta of its sp or iten		Item 7	Severity	L	
	ave bei in stud ary mc cause c made f		SHAPS	Screening	S	
	yzed ha used j noment ed. Bec n was j rRS)			Severity	S	
	Scales analyzed validated or use assessing mome also excluded. I an exception was Scale (UPDRS)		Chapman	Screening	L	
	Scale valid asses also o an ex			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
<u>.</u>	ation. selected were		ea	DSFS- S	Not specified	S	Based on Evatt et al 2008. (5).
mouc	d constip D were sulations		Sialorrhea	DRL	Not specified	S	
IIA nal dysauto (S) ea, dysphagia and of patients with Pl used in other popu		Sig	SCS- PD-S	Not Specified	S		
	7?	lagia	SDQ	Not specified	S		
ONON ntesti s (GII	of sialorrh n studies ed, scales	Up to June 2007?	Dysphagia	SWAL QOL-S	Not specified	S	
DYSAUTO wer gastroi symptoms	DYSAUTONOMIA Upper and lower gastrointestinal dysautonomia symptoms (GIDS) Scales analyzed were used in the assessment of sialorthea, 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		Constipation		scales identif OME III mod		
<u>Ó</u>	ised i as ou ch sc		Š	SCOPA	Screening	R	
anc	ere u used no su ation		ale	AUT	Follow-up	L	
er 8	Upper and		Generic scales	NMS	Screening	R	
dd ₁			ieri		Follow-up	L	
) j			Gen	NMSS	Screening	S	
	Sca Sca for sele				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
			VAS	Screening	R	Based on Cruccu et al
	ain is ain is pathic			Severity	R	2006. (6). Grading was
	red cer this par s neuro		NRS	Screening	S	inferred by the MDS-UPDRS
	is conside in trigger with PD i			Severity	S	Appendix committee chair from the quoted paper plus the
	the pa		VRS	Screening	S	specific references on
	uted wi			Severity	S	pain and PD retrieved from
	associal al stimut pail ury pail		11-likert	Screening	S	Pubmed A full remort
	review on the assessment of neuropathic pain were considered. Pain associated with PD is considered central in pain. However it is also admitted that there are cases where peripheral stimuli are the pain trigger, this pain is ly understood but for the purpose of this chart we consider that primary pain associated with PD is neuropathic.	Up to June 2007		Severity	S	A full report from the task force is still in
			PRS	Screening	NA	preparation but it seems import to invest in characterizing the pain phenomenology in PD before taking the decision about developing a specific scale or
				Severity	L	
			GPS	Screening	L	
Z				Severity	L	
PAIN			MPQ	Screening	L	
		Ω		Severity	L	not.
	sessme		SF-	Screening	R	
	the as: 'ever it		MPQ	Severity	S	
	ew on n. How.nderst.		SSS	Screening	L	
	tic revi			Severity	L	
	vstema uropatl is not		NPS	Screening	L	
	FNS sy e of ne i in PD			Severity	L	
	Scales considered in the EFNS systematic origin what makes it a type of neuropathic probably nociceptive. Pain in PD is not full		NPSI	Screening	S	
				Severity	S	
			CGI	Screening	NA	
				Severity	L	t .

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	Temporal	Scales	Goal:	Grading	Comments
	selection	Window		Diagnostic		
	(criteria)			Screening		
				or Rating		
				Severity		
2	. j		MMP	Not	L	Based on the appendices
GNITION DEMENTIA)	re to age-matched I controls, most non- ted patients with PD are ed in several cognitive Poor performance even in early stages. Only specifically develop for ive impairment in PD			specified		committee
	iched ost non- with PD a cognitive iance evei es. Only develop fr	April 2004	SCOPA-	Not	S	original report.
	-matches, most nts with eral cogormances stages.	pril (Cog	specified		
COGNITION OT DEMENT	o age-mat ontrols, mo patients v in several or perform early stag ecifically o		BAECD	Not	S	
ŎĘ	e to con ted ped in eg in eg speci	Up to		specified		
CO (NOT	Relative to age-matched normal controls, most non-demented patients with PD impaired in several cognitivasks. Poor performance ew occurs in early stages. Only scales specifically develop cognitive impairment in PD		FAB	Not	L	
	Re no de de coc sca			specified		

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	Temporal	Scales	Goal:	Grading	Comments
	selection	Window		Diagnostic		
	(criteria)			Screening		
				or Rating		
				Severity		
			MMSE	Not	L	Based on the appendices
ase	used in ved PD			specified		committee
rise ia	e use	2004	ADAS-	Not	S	original report and one the
n D ent	were reviev		Cog	specified		MDS PDD task
inson Dis Dementia	analyzed ied, peer- tria studie	Up to April	MDRS	Not	R	force 2 nd paper, in press.
kin D	anal: led, l	Up t		specified		in press.
Parkinson Disease Dementia	Scales analyzed were used in published, peer-reviewed PD Dementia studies.		NPI	Not	L	
	Sc Do			specified		

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

Domain	Scales	Temporal	Scales	Goal:	Grading	Comments
	selection	Window		Diagnostic		
	(criteria)			Screening		
				or Rating		
				Severity		
	ii Q		FSS	Not	R	Based on the appendices
	sed i	∞		specified		committee
E	were used reviewed P	2008	MFI	Not	S	original report and a new
<u>5</u>	d we	arch		specified		search of
FATIGUE	analyzed were used in ied, peer-reviewed PD	Up to March	PFS	Not	R	Pubmed made in March 2008.
五	s ana hed, s.	Up t		specified		Analysis was
	Scales ana published, studies.					only preliminary,
	ο c z					made by CS

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
	of of			PSQI	Screening	R	Based on the appendices
3P	Scales analyzed have been designed to assess insomnia and/or quality of sleep in PD studies.				Severity	R	committee original report
			SCOPA	Screening	S	and a new search of Pubmed made	
			Sleep	Severity	S	in March 2008.	
SLE	is inso		<u>&</u>	SDQ	Screening	L	
AL S	o asses		Up to March 2008		Severity	NA	
JRN	gned to	gned to		NSFSS	Screening	L	
NOCTURNAL SLEEP	en desi		Up		Severity	NA	
NON	ave bec			PDSS	Screening	R	
	yzed ha	Scales analyzed hav sleep in PD studies.			Severity	R	
	s analy in PD			MPDSS	Screening	L	
	Scale				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
			ESS	Screening	R	Based on the appendices
	me			Severity	R	committee original report
ESS	ss dayt		SCOPA	Screening	S	and a new search of Pubmed made
DAYTIME SLEEPINESS	ato assesstudies.	80	Sleep Day	Severity	S	in March 2008.
LEE	igned t	Up to March 2008	PDSS	Screening	L	
AE S	ed have been designed "sleep attacks" in PD	to Ma	Item 15	Severity	L	
/III/	ave be	Up	SSS	Screening	L	
DAY	yzed h or "slec			Severity	L	
	Scales analyzed have been designed to assess daytime sleepiness or "sleep attacks" in PD studies.		KSS	Screening	L	
	Scale			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
	mic r es se		SCOPA-	Screening	L	Based on the MDS-UPDRS
	ific for instance scale to PD		AUT	Severity	L	Appendix Committee
NOI	ssing a e spec odoma here a here a tic into		NMS	Screening	L	report and a new search of
ENS	es asse ales ar OH suh nally, t rthosta		Quest	Severity	L	Pubmed made in March 2008.
[LO	ic scallics scall rese scall with o with o	80	NMSS	Screening	L	
HYF	gener ne of the scales PD. A ciated ey have	Up to March 2008		Severity	L	
	H. Son momic dies of sasso but the	to Mai	COMPASS	Screening	L	
TAZ	la nun ling Ol ic autc in stu mpton o OH,	n		Severity	L	
HOS	HOS cluded includ gener tt used aate syj		OGS	Screening	L	
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)			Severity	L		
	ss analyse sym There a fic for loped t exclusi		OHSA	Screening	L	
	Scale relate PD. 7 speci devel (not e coho)			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	Temporal	Scales	Goal:	Grading	Comments
	selection	Window		Diagnostic		
	(criteria)			Screening		
				or Rating		
				Severity		
Z			IIEF	Not	S	Based on the MDS-UPDRS
E 10		80		specified		Appendix
		h 20				Committee
ERECTII 'SFUNC'		Up to March 2008	IIEF-5	Not	S	report and a new
RE FI	text.	to N	SHIM	specified		search of Pubmed made
E		Up				in March 2008.
О	See					

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.

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