INITIAL VISIT PACKET UNIFORM DATA SET (UDS) VERSION 4.0

Form B9: Clinician Judgment of Symptoms



ADRC:	PTID:	Form date:// Visit #: initials:
Language:	Mode:	Key (remote reason): 1=Too cognitively impaired
🗆 1 English	□ 1 In-person	2=Too physically impaired
□₂ Spanish	2 Remote (reason):	3=Homebound or nursing home
	□ 1 Telephone □ 2 Video	4=Refused in-person visit
		5=Other

INSTRUCTIONS: This form is to be completed by the clinician. <u>Questions below are not intended for direct administration to participant</u> or <u>co-participant</u>. For all questions the clinician must use their best judgment about whether symptoms are present and make their estimate when symptoms began based on information from participant and co-participant. For additional clarification and examples, see **UDS Coding Guidebook** for **Form B9**. Check only <u>one</u> box per question.

Section 1 – Changes across domains						
Reported by participant.						
1.	Does the <u>participant</u> report a decline in any cognitive domain (relative to stable baseline prior to onset of current syndrome)?	0 No 1 Yes	8 Could not be assessed / participant is too impaired			
2.	Does the <u>participant</u> report a decline in any motor domain (<i>relative to stable baseline prior to onset of current syndrome</i>)?	0 No 1 Yes	8 Could not be assessed / participant is too impaired			
3.	Does the <u>participant</u> report the development of any significant neuropsychiatric/behavioral symptoms (<i>relative to stable baseline prior to onset</i> of current syndrome)?	0 No 1 Yes	8 Could not be assessed / participant is too impaired			
Repo	orted by co–participant.					
4.	Does the <u>co-participant</u> report a decline in any cognitive domain (<i>relative to stable baseline prior to onset of current syndrome</i>)?	0 No 1 Yes	8 There is no co-participant			
5.	Does the <u>co-participant</u> report a change in any motor domain (relative to stable baseline prior to onset of current syndrome)?	0 No 1 Yes	8 There is no co-participant			
б.	Does the <u>co-participant</u> report the development of any significant neuropsychiatric/behavioral symptoms (<i>relative to stable baseline prior to onset</i> of current syndrome)?	0 No 1 Yes	8 There is no co-participant			
Reported by clinician						
7.	7. Does the participant have any neuropsychiatric / behavioral symptoms, decline in any cognitive domains, or changes in any motor domains?		O No (END FORM HERE) I Yes			
In the following sections record the phenotype of clinically meaningful symptoms or absence of a history of these symptoms, as determined by the clinician's best judgment following the medical history interview with the participant and co-participant.						

Section 2 – Cognitive impairment

Consider if the participant currently is meaningfully impaired, relative to stable baseline prior to onset of current syndrome:				
8.	Based on the clinician's judgment, is the participant currently experiencing meaningful impairment in cognition?	0 No		QUESTION 11)
9.	Indicate whether the participant is meaningfully impaired in the following cognitive domains	or has flu	ctuating	cognition:
	ognitive	No	Yes	Unknown
	9a. Memory — For example, do they forget conversations or dates, repeat questions or statements, or misplace things more than usual?	Do	1	9
	9b. Orientation — For example, do they have trouble knowing the day, month, and year, forget names of people they know well, get lost in familiar locations, or not recognize familiar locations?	0	1	9
	9c. Executive function (<i>judgment, planning, and problem–solving</i>) — Do they have trouble planning complex activities like trips, financial transactions, parties, or group meetings?	0	1	9
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Section 2 – Cognitive impairment continued					
		No	Yes	Unknown	
	9d. Language — Do they have hesitant speech, have trouble finding words, use inappropriate words without self-correction, or have trouble with speech comprehension?	Do	1	9	
	9e. Visuospatial function — Do they have difficulty interpreting visual stimuli or finding their way around in familiar environments?	Πo	1	9	
	9f. Attention/concentration — Does the participant have a short attention span or limited ability to concentrate? Are they easily distracted?	0	1	9	
	9g. Fluctuating cognition — Does the participant exhibit pronounced variation in attention and alertness, noticeably over hours or days—for example, long lapses or periods of staring into space, or times when their ideas have a disorganized flow?	O	1	9	
	9h. Other (SPECIFY):	0	1		
	9i. If any of the cognitive-related behavioral symptoms in 9a-9h are present, at what age did they begin? (The clinician must use their best judgment to estimate an age of onset. If multiple symptoms with different ages of onset are identified, denote the age of the earliest symptom.)				
10.	Mode of onset of cognitive impairment:I GradualIndicate the mode of onset for the most prominent2 Subacuteis causing the participant's complaints and/or affecting the participant's3 Abruptfunction.3 Abrupt	ne mode of onset for the most prominent cognitive problem that			
Sec	tion 3 – Neuropsychiatric symptoms and behavioral changes				
Consider if the participant manifests – in the last month – clinically meaningful neuropsychiatric symptoms or change in behavior relative to stable baseline (<i>i.e., predominant behavioral state prior to the onset of the current syndrome</i>). Clinically meaningful change refers to symptoms or changes that are evident most days in a given four-week period.					
11.	 Based on the clinician's judgment, does the participant manifest clinically meaningful neuropsychiatric symptoms or meaningful change in behavior? 		No (SKIP TO QUESTION 14) 1 Yes		
12.	 Specify the phenotype of clinically meaningful neuropsychiatric symptoms or meaningful change in behavior that has manifested in the last month. 			at has	
Мо	od, motivation, and agitation	No	Yes	Unknown	
	12a. Apathy/withdrawal — Has the participant lost interest in the world around them, lost interest in doing things, or do they lack motivation for starting new activities?	Do	1	9	
	12b. Depressed mood — Does the participant seem sad or depressed, or say that they feel sad or depressed?	Πo	1	9	
	12c. Anxiety — Does the participant seem very nervous, worried, or frightened for no apparent reason? Do they seem very tense or fidgety? Do they seem afraid to be apart from caregivers or from others that they trust?	0	1	9	
	12d. Euphoria — Does the participant seem too cheerful or too happy for no reason, manifest a persistent and abnormally good mood, or find humor where others do not?	0	1	9	
	12e. Irritability — Does the participant get irritated and easily disturbed? Are their moods very interchangeable? Are they abnormally impatient?	Do	1	9	
	12f. Agitation — Is the participant easily distressed or angered and hard to handle, uncooperative, or resistive to care or to help from others?	Πo	1	9	
	12g. If any of the mood–related behavioral changes in 12a–12f are present, at what age did they begin? (<i>The clinician must use their best judgment to estimate an age of onset. If multiple symptoms are identified, denote the age of the earliest symptom.</i>)				

Section 3 – Neuropsychiatric symptoms and behavioral changes continued			
Psychosis and impulse control	No	Yes	Unknown
12h. Visual hallucinations - Does the participant exhibit visual perceptions without a stimulus?	0	1	9
12h1. IF YES, do their hallucinations include patterns that are not definite objects, such as pixelation of flat uniform surfaces?	0	1	9
12h2. IF YES, do their hallucinations include well-formed and detailed images of objects or people, either as independent images or as part of other objects?	0	1	9
12i. Auditory hallucinations - Does the participant exhibit auditory perceptions without a stimulus?	O	1	9
12i1. IF YES, do the auditory hallucinations include simple sounds like knocks or other simple sounds?	O	1	9
12i2. IF YES, do the auditory hallucinations include complex sounds like voices speaking words, or music?	0	1	9
12j. Delusions - Does the participant have fixed, idiosyncratic beliefs that are not true? For example, insisting that others are trying to harm them or steal from them? Have they said that family members or staff are not who they say they are, or that the house is not their home?	Do	1	9
12k. Aggression — Does the participant shout angrily, slam doors, attempt to hit or hurt others, or exhibit other verbally or physically agressive behaviors?	0	1	9
121. If any of the psychosis and impulse control–related behavioral changes in 12h–12k are present, at what age did they begin? (<i>The clinician must use their best judgment to estimate an age of onset. If multiple symptoms are identified, denote the age of the earliest symptom.</i>)			
Personality	No	Yes	Unknown
12m. Disinhibition — Does the participant act impulsively without thinking, say things that are not usually done or said in public, or do things that are embarrassing to caregivers or others, or do they talk personally to strangers or have disregard for personal hygiene?	0	1	9
12n. Personality change — Does the participant exhibit bizarre behavior or behavior uncharacteristic of the participant, such as unusual collecting, suspiciousness (<i>without delusions</i>), unusual dress, or unusual eating behaviors?	0	1	9
120. Loss of empathy — Does the participant fail to take others' feelings into account?	O	1	9
12p. Obsessions and/or compulsions — Does the participant repeatedly and excessively focus on particular ideas or activities, or have they developed new habits, like physical behaviors or stereotypical verbal phrases?	0	1	9
12q. Explosive anger — Does the participant have a "short fuse"? Do they display explosive outbursts of anger or rage?	O	1	9
12r. Substance use — Does the participant currently show evidence of excessive consumption of recreational, psychoactive, or typically abused substances (<i>substantial increase compared with prior habits, and beyond medical necessity if prescribed substance</i>)?	0	1	9
(Check all that apply) 12r1b. 1 S 12r1c. 1 C 12r1d. 1 C 12r1d. 1 C 12r1e. 1 C 12r1f. 1 C 12r1f. 1 C 12r1f. 1 C	Icohol edative/h)piate Cocaine Cannabis Other (SPI		
age did they begin? (The clinician must use their best judgment to estimate an age of onset. If multiple symptoms are identified, denote the age of the earliest symptom.)			

Section 3 – Neuropsychiatric symptoms and behavioral changes continued				
REM sleep			Yes	Unknown
	12t. REM sleep behavior disorder — While sleeping, does the participant appear to repeatedly act out their dreams (<i>e.g., punch or flail their arms, shout, or scream</i>)?	0	1	9
	12t1. IF YES, at what age did the dream enactment behavior begin? (<i>The clinician must use their best judgment to estimate an age of onset.</i>)			
	12t2. Was REM sleep behavior disorder confirmed by polysomnography?	O	1	9
Oth	er	No	Yes	Unknown
	12u. Other behavioral changes (SPECIFY):	0	1	
13.	3. Overall mode of onset for behavioral changes: Indicate the mode of onset for the most prominent behavioral problem that is causing the participant's complaints and/or affecting the participant's function. ¹ 1 Gradual 2 Subacute 3 Abrupt 		4 Other (SPECIFY):	
Sec	tion 4 – Motor changes			
	ider if the participant currently has meaningful change in motor function <u>that represents a cl</u> eline prior to the current syndrome and is potentially due to a disorder affecting the cent			
14.	Based on the clinician's judgment, is the participant currently experiencing any meaningful changes in motor function?	No (SKIP TO QUESTION 19) 1 Yes		
15.	Indicate whether the participant has meaningful change in motor function:			
Mo	or	No	Yes	Unknown
	15a. Gait disorder — Has the participant's walking changed, not specifically due to arthritis, injury, or peripheral neuropathy? Are they unsteady, or do they shuffle when walking, have little or no arm-swing, or drag a foot?	0	1	9
	15b. Falls — Has the participant had an increase in frequency of falls compared with their stable baseline prior to the current syndrome?	O	1	9
	15c. Slowness — Has the participant noticeably slowed down in walking, moving, or writing by hand, other than due to an injury or illness?	0	1	9
	15d. Tremors — Has the participant had rhythmic shaking, especially in the hands, arms, legs, head, mouth, or tongue?		1	9
	15e. Limb weakness — Has the participant noticed a change (<i>abrupt or gradual</i>) in limb function such that an arm and/or leg is weak compared to their prior baseline?		1	9
	15f. Change in facial expression — Has the participant's facial expression changed or become more "wooden," or masked and unexpressive?		1	9
	15g. Change in speech — Has the participant noted a change in speech (<i>abrupt or gradual</i>) such that speech is slurred, and/or the ability to articulate the tongue and lips to form words and sentences has declined compared to their baseline?		1	9
	15h. If changes in motor function are present in 15a–15g, at what age did they begin? (The clinician must use their best judgment to estimate an age of onset. If multiple symptoms are identified, denote the age of the earliest symptom.)			
16.	Mode of onset for motor changes: Indicate the mode of onset for the most prominent motor problem that 2 	4 Other (SPECIFY):		
	is causing the participant's complaints and/or affecting the participant's Subacute function.	 99 U	nknown	
		No	Yes	Unknown
17.	Were changes in motor function suggestive of parkinsonism?		1	9
18.	18. Were changes in motor function suggestive of amyotrophic lateral sclerosis (ALS) (e.g., changes in weakness and/or muscle twitches in one or more limbs, slurred speech, etc.)? □ 0 1 1		9	

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Section 5 – Overall course of decline and predominant domain						
19.	Overall course of decline of cognitive / behavioral / motor syndrome:	 1 Gradually progressive 2 Stepwise 3 Static 4 Fluctuating 5 Improved 8 Not applicable 9 Unknown 				
20.	Indicate the predominant domain that was first recognized as changed in the participant:	 1 Cognition 2 Behavior 3 Motor function 8 Not applicable 9 Unknown 				