

## Data Collection Worksheet

**Please Note:** The Data Collection Worksheet (DCW) is a tool to aid integration of a PhenX protocol into a study. The PhenX DCW is not designed to be a data collection instrument. Investigators will need to decide the best way to collect data for the PhenX protocol in their study. Variables captured in the DCW, along with variable names and unique PhenX variable identifiers, are included in the PhenX Data Dictionary (DD) files.

	<i>Date:</i>	<i>Co-raters:</i>
	<i>Interviewer:</i>	<i>Duration:</i>

I am now going to ask you about your usual sleep patterns.

	<i>INTERVIEWER: Please tell participant that they should not reveal their diagnosis to you.</i>			
	<b>Routine Sleep Schedule</b>			
		<u>N</u> <u>o</u>	<u>Yes</u>	<u>Unk</u>
DASLP99 9	Do you normally work (or attend school) during the day and sleep at night?  <i>INTERVIEWER: If individual is unemployed and out of school, ask about his/her usual time of activity instead.</i>	0	1	9
		<u>Code Response</u>		

DASLP99 9	What is your normal work (or school) and sleep schedule?	1	2	3	
	<p>1 = Always works nights, sleeps during the day</p> <p>2 = Schedule rotates/Shift Work</p> <p>3 = Other, Describe:</p> <hr/> <hr/> <hr/>				
DASLP99 9	(If response = 2) What shift schedule do you most often work?				
	<p>1 = Day Shift (approx. 7am- 3pm)</p> <p>2 = Evening Shift (approx. 3pm- 11pm)</p> <p>3 = Night Shift (approx. 11pm- 7am)</p> <p>4 = Other:</p>	1	2	3	4
	Use the one shift schedule selected for the following questions regarding your workdays.				
	At what time do you usually go to bed:	<u>Time</u>			
DASLP99 9	On a workday or school day?	____:		<input type="checkbox"/> AM	<input type="checkbox"/> PM
DASLP99 9	On a non-work or non-school day ( <i>i.e.</i> , weekend)?	____:		<input type="checkbox"/> AM	<input type="checkbox"/> PM

	About how many minutes does it usually take for you to fall asleep:	<u>Minutes</u>		
DASLP999	On a workday or school day?			
DASLP999	On a non-work or non-school day ( <i>i.e.</i> , <i>weekend</i> )?			
	At what time do you usually wake up:	<u>Time</u>		
DASLP999	On a workday or school day?	_____ : _____	<input type="checkbox"/> AM <input type="checkbox"/> PM	
DASLP999	On a non-work or non-school day ( <i>i.e.</i> , <i>weekend</i> )?	_____ : _____	<input type="checkbox"/> AM <input type="checkbox"/> PM	
		<u>Minutes</u>	<u>Hours</u>	
DASLP999	How long does it take for you to become fully awake from regular sleep ( <i>i.e.</i> , after first opening your eyes in the morning)?			
		<u>Neve</u> <u>r</u>	<u>Sometime</u> <u>s</u>	<u>Al</u> <u>wa</u> <u>ys</u>
DASLP999	Do you use an alarm clock to wake up in the morning?	0	1	2

DASLP999	Do you have great difficulty waking up in the morning?	0	1	2
DASLP999	Do you often have so much trouble waking up that an alarm clock wont wake you and you have to use other methods to wake up?  Describe: _____ _____ _____ _____	0	1	2
DASLP999	When you wake up in the morning or from a nap, do you feel "out of it" and confused?	0	1	2
		<u>Hours</u>	<u>Minutes</u>	
DASLP999	How long does it take for you to fully awaken?			
	How much sleep do you usually get during a typical night:	<u>Hours</u>	<u>Minutes</u>	
DASLP999- DASLP999	On a workday or school day?			
DASLP999- DASLP999	On a non-work or non-school day ( <i>i.e.</i> , <i>weekend</i> )?			
		<u>No</u>	<u>Yes</u>	<u>Unk</u>

DASLP999	Do you usually follow the same sleep schedule (i.e., no more than a 1 hour difference in sleep and wake times) on both work/school and non-work/school days? <i>(or school days and weekends)</i>	0	1	9			
		<u>Hours</u>					
DASLP999	How many hours of sleep per night do you think you need to feel fully rested the next day?						
		<u>Neve</u> <u>r</u>	<u>Sometime</u> <u>s</u>	<u>Al</u> <u>wa</u> <u>ys</u>			
DASLP999	Do you feel awake and refreshed after sleeping?	0	1	2			
		<u>Code Response</u>					
DASLP999	How often do you remember your dreams? That is, dreams that occur during your regular sleep and not while napping.	0	1	2	3	4	9
	<p>0 = Never</p> <p>1 = Rarely (once a month or less)</p> <p>2 = Sometimes (2-4 times per month)</p>				<p>3 = Often (5-15 times per month)</p> <p>4 = Almost always (16-30 times per month)</p> <p>9 = Dont Know</p>		
	Naps	<u>Code Response</u>					
DASLP999	How often do you take naps?	0	1	2	3	4	9

	<p>0 = Never</p> <p>1 = Rarely (once a month or less)</p> <p>2 = Sometimes (2-4 times per month)</p>	<p>3 = Often (5- 15 times per month)</p> <p>4 = Almost Always (16-30 times per month)</p> <p>9 = Dont know</p>						
	<p><i>If respondent never naps, SKIP to Sleep Deprivation.</i></p>							
			<u>Time</u>					
DASLP999	<p>At what time(s) of the day do you usually take naps?</p> <p><i>INTERVIEWER: List up to 3 time(s) of the day.</i></p>		_____ : _____			<input type="checkbox"/> AM <input type="checkbox"/> PM		
DASLP999			_____ : _____			<input type="checkbox"/> AM <input type="checkbox"/> PM		
DASLP999			_____ : _____			<input type="checkbox"/> AM <input type="checkbox"/> PM		
			<u>Hours</u>			<u>Minutes</u>		
DASLP999- DASLP999	<p>How many hours and minutes of sleep do you usually get when you take a nap?</p>							
			<u>Never</u>	<u>Sometimes</u>	<u>Always</u>			
DASLP999	<p>Do you have great difficulty waking up from naps?</p>		0	1	2			

		<u>Code Response</u>					
DASLP999	How often do you dream when you nap?	0	1	2	3	4	9
	<i>0 = Never</i> <i>1 = Rarely (once a month or less)</i> <i>2 = Sometimes (2-4 times per month)</i>						
	<i>3 = Often (5-15 times per month)</i> <i>4 = Almost always (16-30 times per month)</i> <i>9 = Dont Know</i>						
		<u>No</u>	<u>Yes</u>	<u>Unk</u>			
DASLP999	Are these dreams very intense, detailed and vivid, like watching a movie?	0	1	9			
	<b>Sleep Deprivation</b>	<u>Code Response</u>					
DASLP999	How difficult is it for you to adapt to a sleep loss of 3 hours or more (i.e. sleeping 3 or more hours less than you normally do the night before)?	0	1	2	3	9	
	<i>0 = Not at all difficult</i> <i>1 = Not very difficult</i> <i>2 = Somewhat difficult</i>						
	<i>3 = Very difficult</i> <i>9 = Dont know</i>						
<i>INTERVIEWER: For the questions below, first determine whether sleep loss affects these factors. If there is a change following sleep loss, circle whether there is an improvement or a worsening, or an increase or decrease.</i>							

	Does this loss of sleep affect you the next day with respect to...? ( <i>If yes, How?</i> )	No	Yes	<u>Circle One</u>			
DASLP999- DASLP999	...your mood (being sadder or happier)?	0	1	Improves 2	Worsens 3	Both 4	DK 9
DASLP999- DASLP999	...your tendency to be irritable?	0	1	Increases 2	Decreases 3	Both 4	DK 9
DASLP999- DASLP999	...your ability to get your work done?	0	1	Improves 2	Worsens 3	Both 4	DK 9
DASLP999- DASLP999	...how much you eat?	0	1	Increases 2	Decreases 3	Both 4	DK 9
DASLP999- DASLP999	...your desire for chocolate or sweets?	0	1	Increases 2	Decreases 3	Both 4	DK 9
		<u>Code Response</u>					
DASLP999	How quickly after this loss of sleep, do you return to your usual self if you are allowed to sleep as much as you like?	1	2	3	4	9	
	1 = Within 1 day or less 2 = 2 to 3 days 4 = Over 5 days 9 = Dont Know						

	3 = 4 or 5 days										
	<b>Sleep Regularity</b>										
			<u>No</u>	<u>Yes</u>	<u>Unk</u>						
DASLP999	Do you prefer to keep a regular sleep schedule (i.e. one that does not change much from one night to the next)?				0	1	9				
			<u>Code Response</u>								
DASLP999	If you do not keep your regular sleep schedule, how much do you feel "off" (i.e. not your regular self), the next day?				0	1	2	9			
	0 = None, Feel the Same	2 = Yes, A Great Deal Off									
	1 = Yes, Somewhat Off	9 = Dont Know									
	<b>Jet Lag</b>				<u>Code Response</u>						
DASLP999	When you are traveling <b>EAST</b> by air and you cross over several time zones, how quickly do you return to your usual sleeping pattern?				1	2	3	4	7	9	
	1 = Within 1 day or less	4 = Over 5 days	7 = N/A								

	2 = 2 to 3 days 3 = 4 or 5 days	9 = Dont Know					
DASLP999	What about when you are traveling <b>WEST</b> by air over several time zones?  <i>Code same as above.</i>	1	2	3	4	7	9
	<b>Morningness-Eveningness</b>	<u>Code Response</u>					
		<u>Neither</u>	<u>Morning</u>	<u>Evening</u>			
DASLP999	Do you consider yourself to be a morning person ("early bird"), an evening person ("night owl"), or neither?	0	1	2			
		<u>Code Response</u>					
		<u>None</u>	<u>Some</u>	<u>Strong</u>			
DASLP999	How strong is your preference?	0	1	2			
	<b><u>DELAYED SLEEP PHASE SYNDROME</u></b>						
		<u>No</u>	<u>Yes</u>	<u>Unk</u>			
DASLP999	<i>INTERVIEWER: Does respondent consistently fall asleep very late (i.e., 12 a.m. or later) at night AND characterize him/herself as a</i>	0	1	9			

	"night owl" with a "strong preference"?			
	<i>If no, SKIP to Insomnia section</i>			
	When you do not have to maintain a strict schedule (i.e. not dictated by strict work or school schedules, as while on vacation or not working):	<u>Time</u>		
DASLP999	...at what time do you usually <b>go to sleep</b> (i.e. feel sleepy and ready to go to bed)?	_____ : _____	<input type="checkbox"/> AM <input type="checkbox"/> PM	
DASLP999	...at what time do you usually wake up?	_____ : _____	<input type="checkbox"/> AM <input type="checkbox"/> PM	
		<u>No</u>	<u>Yes</u>	<u>Unk</u>
DASLP999	...are these usual sleep and wake times always about the same (i.e. each day during a week of vacation)?	0	1	9
DASLP999	...do you wake up on your own (i.e., without an alarm or other assistance)?	0	1	9
DASLP999	Have you ever tried to force yourself to <b>fall asleep</b> at an (earlier) time than your usual bedtime?	0	1	9
	<i>If no, SKIP to Insomnia Section.</i>			
DASLP999	When you tried to shift your sleep schedule to an earlier bedtime (at least 1 to 2 hours earlier), did you have difficulty falling asleep?	0	1	9

DASLP999	Do attempts to change your sleep/wake schedule tend to make your sleeping difficulties <i>worse</i> ?	0	1	9
	<i>If no, SKIP to Insomnia Section.</i>			
		<u>Weeks</u>	<u>Month</u> <u>s</u>	<u>Years</u>
DASLP999- DASLP999	During the past year, what was the longest period of time that you had these sleeping problems on most nights?			
	<i>If less than one month, SKIP to Insomnia.</i>			
	<b><u>EPISODES/COURSE</u></b>			
	<b><u>Onset</u></b>		<b><u>Age</u></b>	
DASLP999	How old were you when you first began going to sleep very late without being able to adjust your schedule when you tried?			
DASLP999	<b><u>Offset</u></b> How old were you the last time you experienced these problems?			
		<b><u>No</u></b>	<b><u>Yes</u></b>	<b><u>Unk</u></b>
DASLP999	Do you currently experience these problems?	0	1	9
	<b><u>DISTRESS/IMPAIRMENT</u></b>			

	Please look at this scale from 0 to 10, where 0 means <i>no distress/impairment</i> and 10 means <i>very severe</i> problems.	
	Distress	<u>Code Response</u>
DASLP999	How much have your late bedtime and inability to adjust your schedule upset or distressed you?	
	Impairment	<u>Code Response</u>
DASLP999	<u>Social</u> What number describes how much this eveningness tendency has affected your social life and/or relationships with your friends?	
DASLP999	<u>Family</u> What number describes how much this eveningness tendency has affected your relationships with family members?	
DASLP999	<u>School/Work</u> What number describes how much this eveningness tendency has affected your performance in school/work or your relationships with your co-workers, employers, teachers or classmates?	

	<strong>INSOMNIA (SIMPLE AND PSYCHOPHYSIOLOGIC)</strong>		
	Have you ever had frequent problems	<u>No</u>	<u>Yes</u> <u>Unk</u>

DASLP999	1. getting to sleep at the beginning of the night...or	0	1	9
DASLP999	2. staying asleep at night...or	0	1	9
DASLP999	3. falling back to sleep after waking in the middle of the night...  ...which has <i>negatively affected how you function during the following day?</i>	0	1	9
	<i>If no, SKIP to Narcolepsy-Cataplexy section.</i>			
	In the past year, have you...?			
DASLP999	...had difficulty getting to sleep?	0	1	9
DASLP999	...awakened during the night and had a hard time getting back to sleep?	0	1	9
DASLP999	...awakened too early in the morning and couldnt get back to sleep?	0	1	9
		<u>Weeks</u>	<u>Months</u>	<u>Years</u>
DASLP999-DASLP999	What was the longest period of time you had sleeping problems (such as those described above) on most			

	nights during the past year?			
	<i>INTERVIEWER: If respondent endorses <u>less than one month of sleeping problems</u>, SKIP to Narcolepsy-Cataplexy section.</i>			
	Do you experience any of the following <b>during the daytime</b> due to your difficulties falling asleep or staying asleep at night:	<u>No</u>	<u>Yes</u>	<u>Unk</u>
DASLP999	Attention, concentration or memory problems?	0	1	9
DASLP999	Errors or accidents at work or while driving?	0	1	9
DASLP999	Social problems or poor work/school performance?	0	1	9
DASLP999	Fatigue?	0	1	9
DASLP999	Sleepiness?	0	1	9
DASLP999	Feeling tense/muscle tension?	0	1	9
DASLP999	Headaches?	0	1	9
DASLP999	Gastrointestinal symptoms (e.g. upset stomach, nervous stomach)?	0	1	9

DASLP999	Mood changes/problems or irritability?	0	1	9
DASLP999	A lack of motivation or energy to do things (manifested as e.g. procrastination or lack of initiative)?	0	1	9
DASLP999	Concerns or worries about sleep?	0	1	9
	Do you do any of the following <i>during the night</i> when you cannot fall asleep, do you:			
DASLP999	Experience frustration, tension and/or anxiety over not being able to go to sleep?	0	1	9
DASLP999	Look at the clock frequently to see how long you have not been able to fall asleep?	0	1	9
DASLP999	When you are NOT sleeping in your usual bed (e.g. in a hotel room while on vacation, or on your couch watching television), do you still have problems initially getting to sleep, staying asleep, or falling back to sleep after waking up during the night?	0	1	9

	<u>ASSOCIATED CONDITIONS</u>			
	Does your difficulty with insomnia occur at the same time as any of the following events or conditions (i.e. is the insomnia associated temporally with any of the following)?	<u>No</u>	<u>Yes</u>	<u>Unk</u>
DASLP999	...caffeine or other stimulant use?	0	1	9
DASLP999	...other drugs or medications? Specify: _____ _____	0	1	9
DASLP999	...changing schedule? Specify: _____ _____	0	1	9
DASLP999	...noisy or uncomfortable surroundings? Specify: _____ _____	0	1	9
DASLP999	...stress or major life event? Specify: _____ _____	0	1	9
DASLP999	...other disturbances ( <i>i.e. children, pets, etc.</i> )?	0	1	9

	Specify: _____ _____			
DASLP999	...an emotional or mental condition?  Specify: _____ _____	0	1	9
DASLP999	...other medical condition?  Specify: _____ _____	0	1	9
DASLP999	Do you ever have trouble falling asleep or staying asleep, when there seems to be no cause or explanation for it?  Specify: _____ _____	0	1	9
	FOR WOMEN ONLY			
	Has your difficulty with sleeping occurred or worsened during any of the following conditions...	<u>No</u>	<u>Yes</u>	<u>Unk</u>
DASLP999	...pregnancy?			
DASLP999	...menopause? ( <i>ask for women over 35</i> )			
DASLP999	...just before (a few days) menstruation?			
DASLP999	...menstruation?			

	<u>EPISODES/COURSE</u>			
	<u>Episodes</u>	<u>Number Episodes</u>		
DASLP999	How many separate times in your life have you had difficulty getting to sleep, staying asleep or falling back to sleep after waking up during the night (for at least one month)?			
		<u>Age</u>		
DASLP999	<u>Onset</u> How old were you when you first experienced this kind of difficulty with sleeping (for at least one month)?			
DASLP999	<u>Offset</u> How old were you the last time you experienced this insomnia (for at least one month)?			
		<u>No</u>	<u>Yes</u>	<u>Unk</u>
DASLP999	Do you currently experience insomnia?	0	1	9
		<u>Times per Week</u>		
DASLP999-DASLP999	How frequently do you experience insomnia?			
	<u>DISTRESS/IMPAIRMENT</u>			

	Please look at this scale from 0 to 10, where 0 means <i>no distress/impairment</i> and 10 means <i>very severe</i> problems.	
	Distress	<u>Code Response</u>
DASLP999	How much does your insomnia (sleep difficulties) upset or distress you?	
	Impairment	<u>Code Response</u>
DASLP999	<u>Social</u> What number describes how much your insomnia has affected your social life or relationships with your friends?	
		<u>Code Response</u>
DASLP999	<u>Family</u> What number describes how much your insomnia has affected your relationships with family members?	
		<u>Code Response</u>
DASLP999	<u>School/Work</u> What number describes how much your insomnia has affected your performance in school/work or your relationships with your co-workers, employers, teachers or classmates?	

	<u><b>NARCOLEPSY-CATAPLEXY</b></u>			
	<b>A. Daytime Sleepiness</b>	<u>No</u>	<u>Yes</u>	<u>Unk</u>
DASLP999	1. Do you feel so sleepy during the day that it interrupts your normal activities - such as driving, reading, or concentrating at work or school, even when you have had enough sleep the night before?	0	1	9
		<u>Times per</u>		
		<u>Day</u>	<u>Week</u>	<u>Mont h</u>
DASLP999-DASLP999	How often do you feel this way?			
		<u>Week s</u>	<u>Months</u>	<u>Years</u>
DASLP999-DASLP999	What is the longest period of time that you have felt this way (on most days)?			
		<u>No</u>	<u>Yes</u>	<u>Unk</u>
DASLP999	2. During the daytime, do you experience an overwhelming desire to go to sleep - so overwhelming that you cannot resist?	0	1	9
		<u>Times per</u>		
		<u>Day</u>	<u>Week</u>	<u>Mont</u>

				<u>h</u>	
DASLP999-DASLP999	How often does this overwhelming desire to go to sleep occur?				
		<u>Weeks</u>	<u>Months</u>	<u>Years</u>	
DASLP999-DASLP999	What is the longest period of time that you have felt this way (on most days)?				
		<u>Never</u>	<u>Sometimes</u>	<u>Always</u>	
DASLP999	When you do doze off during the day and take a nap, do you find this sleep refreshing?  <i>Describe:</i> _____ _____ _____ _____ _____	0	1	2	
		<u>Code Response</u>			
DASLP999	3. Do you feel that you are sleepier than other people your age?	0	1	2	9
	0 = Not at all 1 = Somewhat	2 = A lot more sleepy 9 = Dont Know			

	<b>B. Cataplexy</b>			
	Do you ever experience periods of muscle weakness, loss of muscle strength or limp muscles in any part of your body (e.g. in the legs or face) during the following situations:	<u>No</u>	<u>Yes</u>	<u>Unk</u>
DASLP999	...when you laugh?	0	1	9
DASLP999	...when you are angry?	0	1	9
DASLP999	...when you hear or tell a joke?	0	1	9

	<u>REM SLEEP BEHAVIOR DISORDER</u>	<u>No</u>	<u>Yes</u>	<u>Unk</u>
DASLP999	1. Have you ever been told that you "act out" your dreams?	0	1	9
		<u>Times per</u>		
		<u>Wee</u> <u>k</u>	<u>Month</u>	<u>Year</u>
DASLP999-DASLP999	How often does this occur?			
		<u>No</u>	<u>Yes</u>	<u>Unk</u>
DASLP999	2. Do you ever move so much during your sleep that you accidentally hit your bed partner (if any) or hurt yourself?	0	1	9
	<i>If no to all (#1 and #2), SKIP to end</i>			

		<u>No</u>	<u>Yes</u>	<u>Unk</u>
DASLP999	Do you have any memory of these event(s)?	0	1	9
DASLP999	Does moving at night disrupt your sleep? (i.e. wake you up at night)	0	1	9
		<u>First</u> <u>Half</u>	<u>Second</u> <u>Half</u>	
DASLP999	During what part of the night do these events most often occur?	1	2	

Protocol source: <https://www.phenxtoolkit.org/protocols/view/121001>