

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.

Score					
Parameter	0	1	2	3	4
Sensory Symptoms	None	Limited to toes	Extend up to and may include ankle	Extend up to and may include knee	Extends above knees
Motor Symptoms					
Legs	None	Trips, catches toes, slaps feet	AFO on at least 1 leg or ankle support	Cane, walker, ankle surgery	Wheelchair most of the time
Arms	None	Difficulty with buttons/zippers	Unable to do buttons or zippers but can write	Can not write or use keyboard	Proximal arms
Pin sensibility	Normal	Reduced in fingers/toes	Reduced up to and may include wrist/ankle	Reduced up to and may include elbow/knee	Reduced above elbow/knee

Vibration	Normal	Reduced at fingers/toes	Reduced at wrist/ankle	Reduced at elbow/knee	Reduced above elbow/knee
Strength					
Legs	Normal	4+, 4, or 4- on foot dorsiflexion	≤3 Foot dorsiflexion	≤3 Dorsiflexion and plantar flexion	Proximal weakness
Arms	Normal	4+, 4, or 4- on intrinsics or finger extensors	≤3 Intrinsics or finger extensors	<5 Wrist extensors	Weak above elbow
Ulnar CMAP	> 6 mV	4.0-5.9 mV	2.0-3.9 mV	0.1-1.9 mV	Absent
(Median)	(>4 mV)	(2.8-3.9)	(1.2-2.7)	(0.1-1.1)	(Absent)
Ulnar SNAP	> 9 uV	6.0 - 8.9 uV	3.0-5.9 uV	0.1-2.9 uV	Absent
(Median)	(>22 uV)	(14.0-21.9)	(7.0-13.9)	(0.1-6.9)	(Absent)

AFO = ankle-foot orthosis

CMAP = compound muscle action potential

SNAP = sensory nerve action potential

Scoring Instructions

Sum scores on all items. Maximum score is 36.

1-10 mildly affected

11-20 moderately affected

21-36 severely affected

Protocol source: <https://www.phenxtoolkit.org/protocols/view/130201>