



## 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.

Please read the following and mark **only one box** beside the description that best represents your child's movement abilities.

My child...

Has difficulty sitting on their own and controlling their head and body posture in most positions

and has difficulty achieving any voluntary control of movement

and needs a specially supportive chair to sit comfortably

and has to be lifted or hoisted by another person to move

Can sit on their own but does not stand or walk without significant support

and therefore relies mostly on wheelchair at home, school, and in the community

and often needs extra body/trunk support to improve arm and hand function

and may achieve self-mobility using a powered wheelchair

Can stand on their own and only walks using a walking aid (such as a walker, rollator, crutches, canes, etc.)

and finds it difficult to climb stairs, or walk on uneven surfaces

and may use a wheelchair when travelling for long distances or in crowds

Can walk on their own without using walking aids, but needs to hold the handrail when going up or down stairs

and often finds it difficult to walk on uneven surfaces, slopes, or in crowds

Can walk on their own without using walking aids, and can go up or down stairs without needing to hold the handrail

**and** walks wherever they want to go (including uneven surfaces, slopes, or in crowds)

**and** can run and jump although their speed, balance, and coordination may be slightly limited

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Protocol source: <https://www.phenxtoolkit.org/protocols/view/131203>