



## 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 adapted 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 adult supervision

and may need extra body/trunk support to improve arm and hand function

and usually needs adult assistance to get in and out of a chair

and may achieve self-mobility using a powered wheelchair or is transported in the community

Can walk on their own using a walking aid (such as a walker, rollator, crutches, canes, etc.)

and can usually get in and out of a chair without adult assistance

and may use a wheelchair when travelling long distances or outside

and finds it difficult to climb stairs or walk on an uneven surface without considerable help

Can walk on their own without using a walking aid, but has difficulty walking long distances or on uneven surfaces

**and** can sit in a normal adult chair and use both hands freely

**and** can move from the floor to standing without adult assistance

**and** needs to hold the handrail when going up or down stairs

**and** is not yet able to run and jump

[ ] Can walk on their own without using a walking aid, including fairly long distances, outdoors, and on uneven surfaces

**and** can move from the floor or a chair to standing without using their hands for support

**and** can go up and down stairs without needing to hold the handrail

**and** is beginning to run and jump

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Protocol source: <https://www.phenxtoolkit.org/protocols/view/131202>