

**Data Collection Worksheet**

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| **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 mark or highlight (e.g., bold or highlight) the answer that is most appropriate.

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| --- | --- | --- | --- | --- | --- | --- |
|  |  | **Never** | **Not often** | **Sometimes** | **Often** | **Very often** |
| 1 | How often do you feel different from other kids because you have SCD? |  |  |  |  |  |
| 2 | How often do you feel people may not like you if they know you have SCD? |  |  |  |  |  |
| 3 | How often do you feel other children are uncomfortable with you because of your SCD? |  |  |  |  |  |
| 4 | How often do you feel other people may not want to be friends with you if they know you have SCD? |  |  |  |  |  |
| 5 | How often do you feel people would not want to go out with you or ask you to parties if they know you have SCD? |  |  |  |  |  |
| 6 | How often do you feel embarrassed about your SCD? |  |  |  |  |  |
| 7 | How often do you keep your SCD a secret from other kids? |  |  |  |  |  |
| 8 | How often do you try to avoid talking to other people about your SCD? |  |  |  |  |  |

Protocol source: <https://www.phenxtoolkit.org/protocols/view/870101>