PhenX Toolkit

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.

For each statement below, circle the number next to how much you agree or disagree with the statement.

1. I can explain what the condition means to people outside my family who may need to know (e.g., teachers, social workers).

   1 [ ] Strongly Disagree

   2 [ ] Disagree

   3 [ ] Neither Agree nor Disagree

   4 [ ] Agree

   5 [ ] Strongly Agree

2. I know who else in my family might be at risk for this condition.

   1 [ ] Strongly Disagree

   2 [ ] Disagree

   3 [ ] Neither Agree nor Disagree

   4 [ ] Agree

   5 [ ] Strongly Agree

3. When I think about the condition in my family, I get upset.

   1 [ ] Strongly Disagree

   2 [ ] Disagree

   3 [ ] Neither Agree nor Disagree

   4 [ ] Agree

5 [ ] Strongly Agree

4. I know what I can do to change how this condition affects me/my children.

1 [ ] Strongly Disagree

2 [ ] Disagree

3 [ ] Neither Agree nor Disagree

4 [ ] Agree

5 [ ] Strongly Agree

5. I am able to make plans for my future.

1 [ ] Strongly Disagree

2 [ ] Disagree

3 [ ] Neither Agree nor Disagree

4 [ ] Agree

5 [ ] Strongly Agree

6. I can make decisions about the condition that may change my future or my child(ren)'s future.

1 [ ] Strongly Disagree

2 [ ] Disagree

3 [ ] Neither Agree nor Disagree

4 [ ] Agree

5 [ ] Strongly Agree