



## 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.

### YOUR FEELINGS ABOUT GENETIC TEST RESULTS

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The following questions ask about how you felt after receiving your genetic test results. Please indicate how much you had each specific feeling in the past week by circling the one answer for each question: not at all, a little, somewhat, a good deal, or a great deal.

1. How upset did you feel about your genetic test result?

0 not at all

1 a little

2 somewhat

3 a good deal

4 a great deal

2. How happy did you feel about your genetic test result?

0 not at all

1 a little

2 somewhat

3 a good deal

4 a great deal

3. How anxious or nervous did you feel about your genetic test result?

0 not at all

1 a little

2 somewhat

3 a good deal

4 a great deal

4. How relieved did you feel about your genetic test result?

0 not at all

1 a little

2 somewhat

3 a good deal

4 a great deal

5. How sad did you feel about your genetic test result?

0 not at all

1 a little

2 somewhat

3 a good deal

4 a great deal

6. How frustrated did you feel about recommendations for your care based on the genetic test result?

0 not at all

1 a little

2 somewhat

3 a good deal

4 a great deal

7. How uncertain did you feel about what your genetic test result means for you?

0 not at all

1 a little

2 somewhat

3 a good deal

4 a great deal

8. How uncertain did you feel about what your genetic test result means for your child(ren) and/or family's risk of disease?

0 not at all

1 a little

2 somewhat

3 a good deal

4 a great deal

9. How much did you feel that you understood clearly your choices for care based on the genetic test result?

0 not at all

1 a little

2 somewhat

3 a good deal

4 a great deal

10. How concerned did you feel that your genetic test result would affect your ability to get or keep health insurance?

0 not at all

1 a little

2 somewhat

3 a good deal

4 a great deal

11. How helpful was the information you received from your genetic test result in planning for the future?

0 not at all

1 a little

2 somewhat

3 a good deal

4 a great deal

12. How concerned did you feel that your genetic test result might make it hard for you to get a job or keep a job?

0 not at all

1 a little

2 somewhat

3 a good deal

4 a great deal

Protocol source: <https://www.phenxtoolkit.org/protocols/view/310901>