



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.

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Please think about the decision you made about genetic testing, genomic testing, and/or receiving additional genetic information; after talking to your [doctor, surgeon, nurse, health professional, etc.]. Please show how you feel about these statements by circling a number from 1 (strongly agree) to 5 (strongly disagree).

1. It was the right decision

- 1 Strongly Agree
- 2 Agree
- 3 Neither Agree Nor Disagree
- 4 Disagree
- 5 Strongly Disagree

2. I regret the choice that was made

- 1 Strongly Agree
- 2 Agree
- 3 Neither Agree Nor Disagree
- 4 Disagree
- 5 Strongly Disagree

3. I would go for the same choice if I had to do it over again

- 1 Strongly Agree
- 2 Agree

3 [] Neither Agree Nor Disagree

4 [] Disagree

5 [] Strongly Disagree

4. The choice did me a lot of harm

1 [] Strongly Agree

2 [] Agree

3 [] Neither Agree Nor Disagree

4 [] Disagree

5 [] Strongly Disagree

5. The decision was a wise one

1 [] Strongly Agree

2 [] Agree

3 [] Neither Agree Nor Disagree

4 [] Disagree

5 [] Strongly Disagree

Scoring:

Subtract 1 from each item, then multiple by 25. Sum all the scores. A total score of 0 indicates no regret, and 100 indicates high regret.

Protocol source: <https://www.phenxtoolkit.org/protocols/view/311301>