



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.

1. My genetic counselor seemed to understand the stresses I was facing...

- 1 Strongly disagree
- 2 Disagree somewhat
- 3 Uncertain
- 4 Agree somewhat
- 5 Agree strongly

2. My genetic counselor helped me to identify what I needed to know to make decisions about what could happen to me...

- 1 Strongly disagree
- 2 Disagree somewhat
- 3 Uncertain
- 4 Agree somewhat
- 5 Agree strongly

3. I felt better about my health after meeting with my genetic counselor...

- 1 Strongly disagree
- 2 Disagree somewhat
- 3 Uncertain
- 4 Agree somewhat
- 5 Agree strongly

4. The genetic counseling session was about the right length of time I needed....

- 1 [] Strongly disagree
- 2 [] Disagree somewhat
- 3 [] Uncertain
- 4 [] Agree somewhat
- 5 [] Agree strongly

5. My genetic counselor was truly concerned about my well-being...

- 1 [] Strongly disagree
- 2 [] Disagree somewhat
- 3 [] Uncertain
- 4 [] Agree somewhat
- 5 [] Agree strongly

6. The genetic counseling session was valuable to me...

- 1 [] Strongly disagree
- 2 [] Disagree somewhat
- 3 [] Uncertain
- 4 [] Agree somewhat
- 5 [] Agree strongly

Protocol source: <https://www.phenxtoolkit.org/protocols/view/311001>