



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. Which of the following sources, if any, did you use to find more information about the genetic test results you received at your last visit? Please rate the usefulness of the sources you used.

1 = not useful at all, 5 = very useful

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|--|---|---|---|---|---|
| <input type="checkbox"/> Family or friends | 1 | 2 | 3 | 4 | 5 |
| <input type="checkbox"/> Facebook | 1 | 2 | 3 | 4 | 5 |
| <input type="checkbox"/> Support groups | 1 | 2 | 3 | 4 | 5 |
| <input type="checkbox"/> My/my child's other doctors | 1 | 2 | 3 | 4 | 5 |
| <input type="checkbox"/> Internet search (i.e., Google, PubMed, etc.) | 1 | 2 | 3 | 4 | 5 |
| <input type="checkbox"/> Books and other print media | 1 | 2 | 3 | 4 | 5 |
| <input type="checkbox"/> Information provided by the doctor who ordered my/my child's genetic test | 1 | 2 | 3 | 4 | 5 |
| <input type="checkbox"/> Other (please specify)_____ | 1 | 2 | 3 | 4 | 5 |
| <input type="checkbox"/> None | | | | | |

If you used the Internet to search for information about the results, please list any websites you found helpful.

Protocol source: <https://www.phenxtoolkit.org/protocols/view/310601>