

## 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.

### Trust in Medical Researchers 12-Item

Participants are first asked the following item regarding willingness to participate: “If you were approached by someone at the [university/institute] to participate in a study, how likely would you be to volunteer to participate in the next 3 months?” Responses were likely, somewhat likely, not likely, or not likely at all to participate.

| 1                     | 2  | 3                     | 4     | 5              |   |   |
|-----------------------|--|-----------------------|-------|----------------|---|---|
| Strongly Disagree     | Disagree   | Neutral               | Agree | Strongly Agree |   |   |
| <b>12-Item Survey</b> |  |                       |       |                |   |   |
| No.                   | Item   | Participant Responses |       |                |   |   |
| 1                     | Doctors who do medical research care only about what is best for each patient.   | 1                     | 2     | 3              | 4 | 5 |
| 2                     | Medical researchers treat people like “guinea pigs.”   | 1                     | 2     | 3              | 4 | 5 |
| 3                     | It’s safe to be in a medical research study.   | 1                     | 2     | 3              | 4 | 5 |
| 4                     | Some doctors do medical research for selfish reasons.  | 1                     | 2     | 3              | 4 | 5 |
| 5                     | Doctors tell their patients everything they need to know about being in a research study.                                  | 1                     | 2     | 3              | 4 | 5 |
| 6                     | A doctor would never ask me to be in a medical research study if the doctor thought there was any chance it might harm me. | 1                     | 2     | 3              | 4 | 5 |
| 7                     | There are some things about medical research that I do not trust at all.   | 1                     | 2     | 3              | 4 | 5 |
| 8                     | A doctor would never recommend something that is not the best treatment, just so he or she can study how it works.         | 1                     | 2     | 3              | 4 | 5 |
| 9                     | Medical researchers have no selfish reasons for doing research studies.  | 1                     | 2     | 3              | 4 | 5 |
| 10                    | Medical researchers do not tell people everything they really need to know about being in a research study.                | 1                     | 2     | 3              | 4 | 5 |

|    |  |   |   |   |   |   |
|----|--|---|---|---|---|---|
| 11 | The only reason doctors do medical research is to help people. | 1 | 2 | 3 | 4 | 5 |
| 12 | I completely trust doctors who do medical research.            | 1 | 2 | 3 | 4 | 5 |

**Scoring:** The scores from the 12 items are summed unweighted, and 12 is subtracted from the total. The total will range from 0-48, with the higher the score, the greater the trust in medical researchers. Items # 2, 4, 7, 10 and 3 are reverse-coded.

Protocol source: <https://www.phenxtoolkit.org/protocols/view/871101>