



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.

Have you had a medical encounter with your patient since you received the genomic result?

Yes

No

1. Before looking at resources other than those provided with the result, when you received the genomic result, how confident did you feel in your...

Knowledge about the condition caused by this gene?

Not at all confident

A little confident

Somewhat confident

Very confident

Ability to explain the result to your patient?

Not at all confident

A little confident

Somewhat confident

Very confident

Ability to answer your patient's questions about the results?

Not at all confident

A little confident

Somewhat confident

Very confident

Ability to personally manage the patient's care based on the result?

Not at all confident

A little confident

Somewhat confident

Very confident

2. To what extent do you agree with the following statements about receiving this unsolicited genomic result?

The result was informative

Strongly disagree

Somewhat disagree

Somewhat agree

Strongly agree

The result was confusing

Strongly disagree

Somewhat disagree

Somewhat agree

Strongly agree

The result was helpful

Strongly disagree

Somewhat disagree

Somewhat agree

Strongly agree

The result was useless

Strongly disagree

Somewhat disagree

Somewhat agree

Strongly agree

Protocol source: <https://www.phenxtoolkit.org/protocols/view/310501>