



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.

Notes: Family Communication is to be administered for both positive and negative results. We feel that participants will still find it important to communicate to other family members that their genetic work-up was negative.

Did you receive a genetic test result for yourself or your child?

Yes

No

If so, did the result provide a genetic diagnosis (was there a positive genetic test result)?

Yes

No

CSER

1. Since receiving your/your child's study results, have you shared the information with any biological family members (blood relatives)?

Yes

I didn't share this information with anyone

I haven't shared this information yet, but plan to in the future

I don't have blood relatives to share this information with

2. Since receiving your/your child's study results, have you shared the information with any of the following blood relatives?

a. My child's other biological parent

Yes

No

N/A

b. My child(ren)

Yes

No

N/A

c. My siblings

Yes

No

N/A

d. My parents

Yes

No

N/A

e. My other biological family members

Yes

No

N/A

If Yes, specify who: _____

eMERGE

3. Thinking about the family members you DID share your genetic test result with, which of the following were important to your decision to share? Check all that apply.

a. I felt obligated to share my genetic test result

b. I was encouraged by my health care provider

c. I made an agreement to tell them before receiving my genetic test result

d. I was encouraged by other family members to share the information

- e. I felt the information could help my family members in making medical decisions
- f. I was asked about my genetic test result by a family member
- g. I wanted to know if a family member had symptoms related to my genetic test result
- h. I needed emotional support from my family member
- i. I needed advice from my family member in making medical decisions
- j. I wanted to provide my family member information about their risk
- k. I wanted to encourage them to get tested
- l. Other

Please specify: _____

Protocol source: <https://www.phenxtoolkit.org/protocols/view/311501>