



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.

Family History Questionnaire

Target child/person items:

1. By age 2, was your child talking in short phrases or sentences?

0 No

1 Yes

99 Don't Know

2. When your child was 2 years old, were you concerned that he/she was having difficulty learning to talk?

0 No

1 Yes

99 Don't Know

3. At this time, do people frequently have trouble understanding your child?

0 No

1 Yes

99 Don't Know

4. Has anyone in your child's family had speech or language therapy?

0 No

1 Yes

99 Don't Know

If Yes, Relationship to child? _____

What for? _____

Family items

Family: Parents and biologically related siblings

5. Has anyone in your child's family had difficulty learning to read or had problems with school work? (e.g., repeated a grade)

0 No

1 Yes

99 Don't Know

If Yes, what are the details? _____

6. Has anyone in your child's family been diagnosed as mentally retarded?

0 No

1 Yes

99 Don't Know

7. Does anyone in your child's family have a hearing difficulty?

0 No

1 Yes

99 Don't Know

8. Has anyone in your child's family been slow in learning to talk?

0 No

1 Yes

99 Don't Know

9. Has anyone in your child's family had any other type of communication disorder such as:

9.1. Stuttering?

0 No

1 Yes

9.2. Is less talkative?

0 [] No

1 [] Yes

9.3. Has a hard time carrying on a conversation?

0 [] No

1 [] Yes

9.4. Doesn't like to read?

0 [] No

1 [] Yes

9.5. Doesn't read well?

0 [] No

1 [] Yes

9.6. Has difficulty thinking of words (s)he wants to say when talking?

0 [] No

1 [] Yes

9.7. Has a poorer vocabulary than other family members?

0 [] No

1 [] Yes

9.8. Is a poor speller?

0 [] No

1 [] Yes

9.9. Has awkward sentence structures when writing or talking?

0 [] No

1 [] Yes

9.10. Mispronounces long words?

0 [] No

1 [] Yes

9.11. Is hard to follow when (s)he tells you something, such as a personal experience?

0 No

1 Yes

9.12. Has difficulty explaining things?

0 No

1 Yes

Protocol source: <https://www.phenxtoolkit.org/protocols/view/200401>