



## 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. Did anyone ever tell you that you had a seizure or convulsion caused by a high fever when you were a child?

Yes

No

Possible

Dont know

2. [Other than the seizure[s] you had because of a high fever] Have you ever had, or has anyone ever told you that you had, a seizure disorder or epilepsy?\*

Yes

No

Possible

Dont know

If the respondent answers "Yes" to question 2, the protocol is complete.

Ask the following questions only if the subject said "NO" to epilepsy or a seizure disorder in question 2.

3. [Other than the seizure[s] you had because of a high fever] Have you ever had, or has anyone ever told you that you had, any of the following...\*

3a. A seizure, convulsion, fit or spell under any circumstances?

Yes

No

Possible

Dont know

3b. Uncontrolled movements of part or all of your body such as twitching, jerking, shaking or going limp?

Yes

No

Possible

Dont know

3c. An unexplained change in your mental state or level of awareness; or an episode of "spacing out" that you could not control?

Yes

No

Possible

Dont know

3d. Did anyone ever tell you that when you were a small child, you would daydream or stare into space more than other children?

Yes

No

Possible

Dont know

3e. Have you ever noticed any unusual body movements or feelings when exposed to strobe lights, video games, flickering lights, or sun glare?

Yes

No

Possible

Dont know

3f. Shortly after waking up, either in the morning or after a nap, have you ever noticed uncontrollable jerking or clumsiness, such as dropping things or things suddenly "flying" from your hands?

Yes

No

Possible

Dont know

3g. Have you ever had any other type of repeated unusual spells?

Yes

No

Possible

Dont know

\*Phrase "Other than the seizure[s] you had because of a high fever" added only if subject responded "yes" or "possible" to question 1.

Protocol source: <https://www.phenxtoolkit.org/protocols/view/130401>