



## 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 of Epilepsy Screening Interview<sup>a</sup>

1. Did anyone ever tell you that (he/she) had a seizure or convulsion caused by a high fever when (he/she) was a child?

Yes

No

Possible

Don't know

2. (Other than the seizure/s) (he/she) had because of a high fever) Has (he/she) ever had, or has anyone ever told you that (he/she) had, a seizure disorder or epilepsy?<sup>b</sup>

Yes

No

Possible

Don't know

Ask the following questions only if proband said "no" to epilepsy or a seizure disorder in Q2. Otherwise go to next part of interview.

3. (Other than the seizure/s) (he/she) had because of a high fever) Has (he/she) ever had, or has anyone ever told you that (he/she) had, any of the following...<sup>b</sup>

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

Yes

No

Possible

Don't know

B. Uncontrolled movements of part or all of (his/her) body such as twitching, jerking, shaking, or going limp?

Yes

No

Possible

Don't know

C. An unexplained change in (his/her) mental state or level of awareness, or an episode of "spacing out" that (he/she) could not control?

Yes

No

Possible

Don't know

D. Did anyone ever tell you that when (he/she) was a small child, (he/she) would daydream or stare into space more than other children?

Yes

No

Possible

Don't know

E. Has (he/she) ever noticed any unusual body movements or feelings when exposed to strobe lights, video games, flickering lights, or sun glare?

Yes

No

Possible

Don't know

F. Shortly after waking up, either in the morning or after a nap, has (he/she) ever noticed uncontrollable jerking or clumsiness, such as dropping things or things suddenly "flying" from (his/her) hands?

Yes

No

Possible

Don't know

G. Has (he/she) ever had any other type of repeated unusual spells?

Yes

No

Possible

Don't know

<sup>a</sup> Syntax shown is for living relatives. For deceased relatives, syntax can be modified accordingly, e.g., "Did your (he/she) ever have ..." instead of "Has (he/she) ever had..."

<sup>b</sup> The phrase "Other than the seizure/s [he/she] had because of a high fever" is added only if the subject responded "yes" or "possible" to question 1.

Protocol source: <https://www.phenxtoolkit.org/protocols/view/130402>