



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.

Questions about Mother

1. Has a doctor ever told your mother that she has Alzheimers Disease?

(Medical doctors include specialists such as Neurologists, Dermatologists, Psychiatrists, Ophthalmologists, Osteopaths, Cardiologists, as well as family doctors, internists and physicians assistants. Also include diagnoses made by Nurses and Nurse Practitioners.)

1 YES, GO TO Question 3

5 NO

7 [IF VOLUNTEERED] NOT ALZHEIMERS DISEASE, GO TO Question 3

8 DK

9 RF

2. Has a doctor ever told your mother that she has dementia, senility or any other serious memory impairment?

1 YES

5 NO

8 DK

9 RF

3. About how old was she when she (died/passed away)?

[INTERVIEWER: PROBE IF NECESSARY]

AGE _____ (go to question 3b)

DK (go to question 4)

RF

3b. In what month and year did she (die/pass away)?

MONTH _____

DK

RF

YEAR _____

DK

RF

Questions about Father

4. Has a doctor ever told your father that he has Alzheimers Disease?

(Medical doctors include specialists such as Neurologists, Dermatologists, Psychiatrists, Ophthalmologists, Osteopaths, Cardiologists, as well as family doctors, internists and physicians assistants. Also include diagnoses made by Nurses and Nurse Practitioners.)

1 YES, GO TO Question 6

5 NO

7 [IF VOLUNTEERED] NOT ALZHEIMERS DISEASE, GO TO Question 6

8 DK

9 RF

5. Has a doctor ever told your father that he has dementia, senility or any other serious memory impairment?

1 YES

5 NO

8 DK

9 RF

6. About how old was he when he (died/passed away)?

[INTERVIEWER: PROBE IF NECESSARY]

AGE _____

DK

RF

6b. In what month and year did he (die/pass away)?

MONTH_____

DK

RF

YEAR_____

DK

RF

Protocol source: <https://www.phenxtoolkit.org/protocols/view/250801>