



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. At the present time, would you say your eyesight using both eyes (with glasses or contact lenses, if you wear them) is:

(READ CATEGORIES)

- 1 excellent
- 2 good
- 3 fair
- 4 poor
- 5 very poor
- 6 completely blind
- 8 refused
- 9 DK

CATARACT-RELATED QUESTIONS:

2. Has a doctor ever told you that you had cataracts in either eye?

- 1 yes
- 2 no (skip to Q4)
- 8 refused (skip to Q4)
- 9 DK (skip to Q4)

3. Did you ever have cataract surgery?

- 1 yes
- 2 no

8 [] refused

9 [] DK

4. Do or did any of your relatives have cataracts?

1 [] yes

2 [] no (skip to Q5)

8 [] refused (skip to Q5)

9 [] DK (skip to Q5)

4a. Which relative(s)? We are only interested in blood relatives.

(READ CATEGORIES AND CODE ALL THAT APPLY)

01 [] mother

02 [] father

03 [] sister (ask Q4b)

04 [] brother (ask Q4b)

05 [] daughter (ask Q4b)

06 [] son (ask Q4b)

07 [] maternal grandmother

08 [] maternal grandfather

09 [] paternal grandmother

10 [] paternal grandfather

11 [] mothers sister (ask Q4b)

12 [] mothers brother (ask Q4b)

13 [] fathers sister (ask Q4b)

14 [] fathers brother (ask Q4b)

15 [] other relative

98 [] refused

99 [] DK

4b. How many of your [RELATIVE(S)] have, had, or were suspected of having cataracts?

(CODE REFUSED AS "98", DONT KNOW AS "99")

__ sisters

__ brothers

__ daughters

__ sons

__ mothers sisters

__ mothers brothers

__ fathers sisters

__ fathers brothers

98 [] refused

99 [] DK

GLAUCOMA-RELATED QUESTIONS:

5. Has a doctor ever told you that you had glaucoma, that is, high pressure in the eyes, in either eye?

1 [] yes

2 [] no (skip to Q9)

8 [] refused (skip to Q9)

9 [] DK (skip to Q9)

6. Have you ever been treated for your glaucoma?

1 [] yes

2 [] no (skip to Q9)

8 [] refused (skip to Q9)

9 [] DK (skip to Q9)

7. In the past 12 months, how many times have you seen an eye doctor for your glaucoma?

__ # times

98 [] refused

99 [] DK

8. What treatment or treatments are you receiving or did you receive for your glaucoma:

(READ CATEGORIES AND CODE ALL THAT APPLY)

8a. eye drops?

1 [] yes

2 [] no

8 [] refused

9 [] DK

8b. Laser?

1 [] yes

2 [] no

8 [] refused

9 [] DK

8c. Surgery?

1 [] yes

2 [] no

8 [] refused

9 [] DK

8d. Other?

1 [] yes (specify_____)

2 [] no

8 [] refused

9 [] DK

9. Do or did any of your relatives have glaucoma?

1 yes

2 no (skip to Q10)

8 refused (skip to Q10)

9 DK (skip to Q10)

9a. Which relative(s)? We are only interested in blood relatives.

(READ CATEGORIES AND CODE ALL THAT APPLY)

01 mother

02 father

03 sister (ask Q9b)

04 brother (ask Q9b)

05 daughter (ask Q9b)

06 son (ask Q9b)

07 maternal grandmother

08 maternal grandfather

09 paternal grandmother

10 paternal grandfather

11 mothers sister (ask Q9b)

12 mothers brother (ask Q9b)

13 fathers sister (ask Q9b)

14 fathers brother (ask Q9b)

15 other relative

98 refused

99 DK

9b. How many of your [RELATIVE] have, had, or were suspected of having glaucoma?

(CODE REFUSED AS "98", DONT KNOW AS "99")

__ sisters

brothers

daughters

sons

mothers sisters

mothers brothers

fathers sisters

fathers brothers

98 refused

99 DK

MACULAR DEGENERATION-RELATED QUESTIONS:

10. Has a doctor ever told you that you had macular degeneration – sometimes called hardening of the arteries – in the back of the eye, damage to the back part of your eye, the retina, or senile macular degeneration?

1 yes

2 no

8 refused

9 DK

11. Do or did any of your relatives have macular degeneration?

1 yes

2 no (skip to Q12)

8 refused (skip to Q12)

9 DK (skip to Q12)

11a. Which relative(s)? We are only interested in blood relatives.

(READ CATEGORIES AND CODE ALL THAT APPLY)

01 mother

02 father

03 sister (ask Q11b)

- 04 [] brother (ask Q11b)
- 05 [] daughter (ask Q11b)
- 06 [] son (ask Q11b)
- 07 [] maternal grandmother
- 08 [] maternal grandfather
- 09 [] paternal grandmother
- 10 [] paternal grandfather
- 11 [] mothers sister (ask Q11b)
- 12 [] mothers brother (ask Q11b)
- 13 [] fathers sister (ask Q11b)
- 14 [] fathers brother (ask Q11b)
- 15 [] other relative
- 98 [] refused
- 99 [] DK

11b. How many of your [RELATIVE] have, had, or were suspected of having macular degeneration?

(CODE REFUSED AS "98", DONT KNOW AS "99")

- __ sisters
- __ brothers
- __ daughters
- __ sons
- __ mothers sisters
- __ mothers brothers
- __ fathers sisters
- __ fathers brothers
- 98 [] refused

99 [] DK

DIABETIC RETINOPATHY-RELATED QUESTIONS:

12. Has a medical doctor ever told you that diabetes has affected blood vessels in your eyes or that you had diabetic retinopathy or diabetic eye disease?

1 [] yes

2 [] no (skip to end)

8 [] refused (skip to end)

9 [] DK (skip to end)

13. Did you ever have laser treatment or surgery for your diabetic eye disease?

1 [] yes, laser treatment

2 [] yes, surgery

3 [] yes, both

4 [] no (skip to end)

8 [] refused (skip to end)

9 [] DK (skip to end)

13a. How many different times have you had laser treatment or surgery for diabetic eye disease?

___ # times

98 [] refused

99 [] DK

Protocol source: <https://www.phenxtoolkit.org/protocols/view/110901>