PhenX Toolkit

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. During the past 12 months have you noticed (name of child) frequently squinting?

1 [ ] yes

2 [ ] no

8 [ ] refused

9 [ ] dont know

2. During the past 12 months has (name of child) had difficulty drawing or coloring?

1 [ ] yes

2 [ ] no

3 [ ] unable to color

8 [ ] refused

9 [ ] dont know

3. During the past 12 months has (name of child) appeared to have difficulty seeing?

1 [ ] yes

2 [ ] no

8 [ ] refused

9 [ ] dont know

4. Does (name of child) close one eye when he/she is in bright sun light?

1 [ ] yes

2 [ ] no

8 [ ] refused

9 [ ] dont know

5. Does (name of child) close or cover one eye when he/she is concentrating?

1 [ ] yes

2 [ ] no

8 [ ] refused

9 [ ] dont know

6. When was (name of child)s last complete eye examination, one that included dilating of pupils where the doctor used bright lights to look in the back of his/her eyes? (this would have made the child temporarily sensitive to bright light)

1 [ ] within past 12 months

2 [ ] 1-3 years ago

3 [ ] 3-5 years ago

4 [ ] never

8 [ ] refused

9 [ ] dont know

7. Has a doctor ever told you that (name of child) had amblyopia, that is poor vision that cannot be corrected with glasses or contact lenses?

1 [ ] yes

2 [ ] no (skip to Q9)

8 [ ] refused (skip to Q9)

9 [ ] dont know (skip to Q9)

a. Was that his/her...

1 [ ] right eye

2 [ ] left eye

3 [ ] both

8 [ ] refused

9 [ ] dont know

8. Has the child ever been treated in the past for amblyopia, that is poor vision that cannot be corrected with glasses or contact lenses, or needing to wear an eye patch?

1 [ ] yes

2 [ ] no

8 [ ] refused

9 [ ] dont know

9. Do or did any of his/her relatives have amblyopia that is, poor vision that cannot be corrected with glasses or contact lenses?

1 [ ] yes

2 [ ] no (skip to Q10a)

8 [ ] refused (skip to Q11)

9 [ ] dont know (skip to Q11)

10a. Which relative(s)? We are only interested in blood relatives.

(READ CATEGORIES AND CODE ALL THAT APPLY)

1 [ ] mother

2 [ ] father

3 [ ] both parents

4 [ ] sister (ask Q10b)

5 [ ] brother (ask Q10b)

6 [ ] grandparents (ask Q10b)

7 [ ] other relative (specify:_____) (ask Q10b)

8 [ ] refused

9 [ ] dont know

10b. How many of his/her (relative) have, had, or were suspected of having amblyopia?

(code refused as 8, dont know as 9)

___ sisters

___ brothers

___ grandparents

___ other relatives

8 [ ] refused

9 [ ] dont know

11. Does (name of child) have strabismus — that is one or both eyes are turned in, or turned out, or up or down, or crossed or wall eyes?

1 [ ] yes

2 [ ] no (skip to Q13)

8 [ ] refused (skip to Q13)

9 [ ] dont know (skip to Q13)

a. Was that his/her.....

(READ CATEGORIES)

1 [ ] right eye

2 [ ] left eye

3 [ ] both

8 [ ] refused

9 [ ] dont know

12. Has (name of child) ever been treated for his/her strabismus that is if one or both eyes are turned in, or turned out, or up or down?

1 [ ] yes

2 [ ] no (skip to Q13)

8 [ ] refused (skip to Q13)

9 [ ] dont know (skip to Q13)

12a. What treatment did (name of child) receive?

1 [ ] glasses or contact lenses

2 [ ] patching

3 [ ] eye drops

4 [ ] vision therapy

5 [ ] eye muscle surgery

6 [ ] botulinum injections

7 [ ] other (specify:_____)

8 [ ] none

88 [ ] refused

99 [ ] dont know

13. Do or did any of his/her relatives have strabismus that is if one or both eyes are turned in, or turned out, or up or down?

1 [ ] yes

2 [ ] no (skip to Q15)

8 [ ] refused (skip to Q15)

9 [ ] dont know (skip to Q15)

14a. Which relative(s)? We are only interested in blood relatives

(READ CATEGORIES AND CODE ALL THAT APPLY)

1 [ ] mother

2 [ ] father

3 [ ] both parents

4 [ ] sister (ask Q14b)

5 [ ] brother (ask Q14b)

6 [ ] grandparents (ask Q14b)

7 [ ] other relative (specify:_____) (ask Q14b)

8 [ ] refused

9 [ ] dont know

14b. How many of his/her (relative) have, had, or were suspected of having

strabismus?

(code refused as 8, dont know as 9)

___ sisters

___ brothers

___ grandparents

___ other relatives

8 [ ] refused

9 [ ] dont know

15. Has a doctor ever told you that (name of child) has myopia (nearsightedness) or needs to wear glasses to see far away?

1 [ ] yes

2 [ ] no (skip to Q17)

8 [ ] refused (skip to Q17)

9 [ ] dont know (skip to Q17)

a. Was that his/her...

(READ CATEGORIES)

1 [ ] right eye

2 [ ] left eye

3 [ ] both

8 [ ] refused

9 [ ] dont know

16. Has name of child ever been treated for his/her myopia (nearsightedness)?

1 [ ] yes

2 [ ] no (skip to Q17)

8 [ ] refused (skip to Q17)

9 [ ] dont know (skip to Q17)

a. What treatment did (name of child) receive?

1 [ ] yes

2 [ ] no

3 [ ] glasses or contact lenses

4 [ ] none

5 [ ] other (specify:_____)

8 [ ] refused

9 [ ] dont know

b. In the past 12 months, how many times has he/she seen an eye doctor for his/her myopia (nearsightedness)?

_____ # times

8 [ ] refused

9 [ ] dont know

17. Do or did any of his/her relative have myopia or (nearsightedness)?

1 [ ] yes

2 [ ] no (skip to Q19)

8 [ ] refused (skip to Q19)

9 [ ] dont know (skip to Q19)

18a. Which relative(s)? We are only interested in blood relatives.

(READ CATEGORIES AND CODE ALL THAT APPLY)

1 [ ] mother

2 [ ] father

3 [ ] both parents

4 [ ] sister (ask Q18b)

5 [ ] brother (ask Q18b)

6 [ ] grandparents (ask Q18b)

7 [ ] other relative (specify:_____) (ask Q18b)

8 [ ] refused

9 [ ] dont know

18b. How many of his/her (relative) have, or had myopia or nearsightedness?

(code refused as 8, dont know as 9)

___ sisters

___ brothers

___ grandparents

___ other relatives

8 [ ] refused

9 [ ] dont know

19. Does your child have or has (he/she) had any other eye or vision problems?

1 [ ] yes

2 [ ] no (skip to end)

8 [ ] refused (skip to end)

9 [ ] dont know (skip to end)

a. What treatment did (name of child) receive?

Specify:_____

b. When did your child receive this treatment?

Date:_____

20. Has a doctor ever told you that (name of child, for each child) ever had:

a. cataract?

1 [ ] yes

2 [ ] no

8 [ ] refused

9 [ ] dont know

(if yes) type of treatment:_____

(if yes) when:_____

b. glaucoma?

1 [ ] yes

2 [ ] no

8 [ ] refused

9 [ ] dont know

(IF YES) type of treatment:_____

(IF YES) when:_____

c. retinopathy of prematurity?

1 [ ] yes

2 [ ] no

8 [ ] refused

9 [ ] dont know

(IF YES) type of treatment:_____

(IF YES) when:_____

d. eye tumor/retinoblastoma?

1 [ ] yes

2 [ ] no

8 [ ] refused

9 [ ] dont know

(IF YES) type of treatment:_____

(IF YES) when:_____

e. optic nerve hypoplasia?

1 [ ] yes

2 [ ] no

8 [ ] refused

9 [ ] dont know

(IF YES) type of treatment:_____

(IF YES) when:_____

f. nasolacrimal duct obstruction?

1 [ ] yes

2 [ ] no

8 [ ] refused

9 [ ] dont know

(IF YES) type of treatment:_____

(IF YES) when:_____

g. cortical visual impairment?

1 [ ] yes

2 [ ] no

8 [ ] refused

9 [ ] dont know

(IF YES) type of treatment:_____

(IF YES) when:_____

h. other? (specify:_____)

1 [ ] yes

2 [ ] no

8 [ ] refused

9 [ ] dont know

(IF YES) type of treatment:_____

(IF YES) when:_____