



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. Have you ever had a crossed or wandering eye (amblyopia)?

yes

no

Im not sure

2. Have you ever had double vision?

yes

no

Im not sure

3. Do you ever tilt your head when looking straight?

yes

no

Im not sure

4. Have you ever undergone eye muscle surgery?

yes

no

Im not sure

5. Have you ever worn a patch or used eye drops (atropine penalization) for eye correction?

yes

no

Im not sure

6. Have you ever worn glasses or contacts?

yes

no

Im not sure

7. If you answered YES to any of the above questions (questions 1-6), please provide further details (i.e. age of onset of eye condition, dates of surgery, name of procedure if known, reason for glasses, etc.) _____

8. Do you have a coloboma? (Absence or defect of ocular tissue ranging from a small pit in the optic disk to extensive defects in the iris, ciliary body, choroid, retina, or optic disk)

yes

no

Im not sure

9. Do you have microphthalmia? (Abnormally small eye)

yes

no

Im not sure

10. Do you have epibulbar dermoids? (Eye tumors that are not recurrent or progressive)

yes

no

Im not sure

11. Do you have any abnormal ocular features? (eg. epicanthal folds-tissue overlapping the nasal corner of the eye, telecanthus- increased distance between the inner corners of the eyes, slanting of the palpebral fissure(s)-opening for the eyes between the eyelids?)

yes

no

Im not sure

12. Do you have any retinal defects? (retinal tears, detachments, etc.)

yes

no

Im not sure

13. Do you have any visual impairment other than previously noted?

yes

no

Im not sure

14. If you answered YES to any question above (questions 8-13), please describe:

Family Ocular History Chart:

Please complete by indicating as appropriate:

15. Glasses before age 6:

Mother

Father

Brother

Sister

♦ sibling through mother/father

Grandfather/mother

Aunt/uncle

Other (specify _____)

16. Patching:

Mother

Father

Brother

Sister

♦ sibling through mother/father

- Grandfather/mother
- Aunt/uncle
- Other (specify _____)

17. Eye muscle surgery:

- Mother
- Father
- Brother
- Sister
- ♦ sibling through mother/father
- Grandfather/mother
- Aunt/uncle
- Other (specify _____)

Protocol source: <https://www.phenxtoolkit.org/protocols/view/111001>