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.

Hearing impairment

Please only give one answer to each question. When the question calls for you to enter a year field, then please enter as yyyy.

1. Do you have any difficulty with your hearing?

[ ] No

[ ] Yes

If "YES,"

1.1. In which ear(s) do you have a hearing difficulty?

[ ] Left

[ ] Right

[ ] Both

1.2. At what age did you first notice a hearing difficulty?

[ ] I have had a hearing difficulty since I was born

[ ] My hearing difficulty developed during my childhood years (before the age of 15)

[ ] My hearing difficulty developed between the ages of 15 and 40

[ ] My hearing difficulty developed after the age of 40

1.3. How quickly did your hearing difficulty develop?

[ ] Suddenly (over a few days)

[ ] Over a few months

[ ] Over several years

1.4. Do you know the reason for your hearing difficulty? (If there is a separate cause for each of your ears, please note them accordingly).

[ ] I have no idea about the cause of my hearing problem

[ ] Yes

_____

_____

1.5. Does your hearing vary from day to day?

[ ] No

[ ] Yes, in both ears

[ ] Yes, in my left ear

[ ] Yes, in my right ear

2. Do you find it very difficult to follow a conversation if there is background noise (e.g., TV, radio, children playing)?

[ ] No

[ ] Yes

3. Are you particularly sensitive to loud sounds?

[ ] No

[ ] Yes

4. Do you sometimes feel a fullness or blockage in your ears?

[ ] No

[ ] Yes, in my left ear

[ ] Yes, in my right ear

[ ] Yes, in both ears

5. Nowadays, do you ever get noises in your head or ears (tinnitus) which usually last longer than five minutes?

[ ] No

[ ] Yes

Ear diseases and balance

6. Have you ever had an ear disease that has caused your hearing to get worse?

[ ] No

[ ] Yes

7. Have you ever had discharge of blood or pus, or smelly discharge (not wax) from either ear?

[ ] No

[ ] I don't know

[ ] From my left ear

[ ] From my right ear

[ ] From both ears

8. Have you ever had an ear operation?

[ ] No

[ ] I don't know

[ ] Yes

If "YES," please also answer the following questions (a–c). Please fill in one row for each operation.

	a. Write down what type of operation, or why the operation was performed	b. Which ear?	c. Which year? (approximately)
8.1.		[ ] left ear [ ] right ear	
8.2.		[ ] left ear [ ] right ear	

8.3.		[ ] left ear [ ] right ear	
8.4.		[ ] left ear [ ] right ear	

9. Have you ever suffered from attacks of dizziness in which things seem to spin around you?

[ ] No

[ ] Yes, within the last year

[ ] Yes, more than a year ago

10. Do you feel unsteady when walking in the dark?

[ ] No

[ ] Yes

Hereditary Factors

From a genetical point of view, it is important that we establish where your ancestors originated from.

11. Concerning your grandparents:

11.1. Where did your mother's father (your maternal grandfather) originate from?

Country:_____ Region: _____

11.2. Where did your mother's mother (your maternal grandmother) originate from?

Country:_____ Region: _____

11.3. Where did your father's father (your paternal grandfather) originate from?

Country:_____ Region: _____

11.4. Where did your father's mother (your paternal grandmother) originate from?

Country:_____ Region: _____

12. As far as you know, does/did your mother have hearing problems?

[ ] No

[ ] Yes

If “YES,”

12.1. What was her year of birth? _____

12.2. What was her occupation? _____

12.3. At what age did her hearing problems start? _____

12.4. What is/was the cause of her hearing problem (if known)?
_____

13. If she is dead, how old was she when she died? _____

14. As far as you know does/did your father have hearing problems?

[ ] No

[ ] Yes

If “YES,”

14.1. What was his year of birth? _____

14.2. What was his occupation? _____

14.3. At what age did his hearing problems start? _____

14.4. What is/was the cause of his hearing problems (if known)? _____

15. If he is dead, how old was he when he died? _____

16. Do you have any brothers or sisters with normal hearing?

[ ] No

[ ] Yes: (how many of your brothers/sisters have normal hearing?) _____

17. Do you have any brothers or sisters with hearing difficulties?

[ ] No

[ ] Yes: (how many of your brothers/sisters have hearing difficulties?) _____

If "YES," please answer the following questions (a–d). Please fill in one row for each brother/sister with hearing difficulties.**

	a. Sex	b. Year of birth	c. Age at onset of hearing difficulties	d. Cause of hearing difficulties (if known)
17.1.	[ ] M [ ] F			
17.2.	[ ] M [ ] F			
17.3.	[ ] M [ ] F			
17.4.	[ ] M [ ] F			

** If needed, you can add extra copies of this page.

18. Do you have any children with normal hearing?

[ ] No

[ ] Yes: (how many of your children have normal hearing?) _____

19. Do you have any children with hearing difficulties?

[ ] No

[ ] Yes: (how many of your children have hearing difficulties?) _____

If "YES," please also answer the following questions (a–d). Please fill in one row for each child with hearing difficulties.**

	a. Sex	b. Year of birth	c. Age at onset of hearing difficulties	d. Cause of hearing difficulties (if known)

[ ]
19.1. M
[ ] F

[ ]
19.2. M
[ ] F

[ ]
19.3. M
[ ] F

[ ]
19.4. M
[ ] F

** If needed, you can add extra copies of this page.

20. Do you have uncles, aunts, cousins, nephews, or nieces with hearing difficulties?

[ ] No

[ ] Yes

21. Do you know if any of your relatives have already participated in this investigation?

[ ] As far as I know, none of my relatives has already participated in this investigation.

[ ] One of my relatives has already participated in this investigation (please write down the name of your relative and the relation between you) _____

General Health

22. Do you suffer from migraine?

[ ] No

[ ] Yes

If “YES,”

22.1. How often do you generally have attacks?

[ ] Often (more than one attack a month)

[ ] Regularly (an attack once a month on average)

[ ] Sporadically (between 4 and 10 times a year)

[ ] Rarely (less than one attack every 3 months)

23. Have you ever suffered a hearing loss from meningitis or encephalitis?

[ ] No

[ ] I don't know

[ ] Yes: in _____ (write down in which year(s) approximately)

24. Have you ever had a whiplash injury?

[ ] No

[ ] I don't know

[ ] Yes: in _____ (write down in which year(s) approximately)

25. Have you ever been knocked unconscious (e.g., in a traffic accident, contact sport, a fight or after a fall)?

[ ] No

[ ] I don't know

[ ] Yes: in _____ (write down in which year(s) approximately)

26. Have you ever had a heart attack?

[ ] No

[ ] Yes: in _____ (write down in which year(s) approximately)

27. Have you ever had heart surgery?

[ ] No

[ ] Yes

If "YES,"

27.1. What operation(s)? (Please describe)

_____

_____

27.2. In which year(s) approximately? _____

28. Have you ever had coronary artery catheterization?

[ ] No

[ ] Yes

If “YES,”

28.1. What type of intervention(s) (e.g., stent, balloon dilatation)?
_____

_____

28.2. In which year(s) approximately? _____

29. Have you ever had a stroke?

[ ] No

[ ] I don’t know

[ ] Yes: in _____ (write down in which year(s) approximately)

30. Have you ever had an operation on your carotid artery?

[ ] No

[ ] I don’t know

[ ] Yes: in _____ (write down in which year(s) approximately)

31. Do you suffer from intermittent claudication? (This is if you can't walk more than 200 metres, because you get cramps in your legs, and when you stand still for a moment the pain gets better)

[ ] No

[ ] I don’t know

[ ] Yes

32. Do you have other problems with your heart or circulation?

[ ] No

[ ] Yes: _____ (please write down which problems)

33. Do you suffer from diabetes?

[ ] No

[ ] I don’t know

[ ] Yes

If “YES,”

33.1. Do you need insulin?

[ ] No

[ ] Yes

34. Please indicate if you suffer from one or more of the following diseases:

If you suffer from one or more of these diseases, please describe your disease on the last row (34.14).

34.1. Osteoporosis

[ ] No

[ ] Yes

34.2. Osteoarthritis

[ ] No

[ ] Yes

34.3. Multiple sclerosis (MS)

[ ] No

[ ] Yes

34.4. Epilepsy

[ ] No

[ ] Yes

34.5. Lung problems

[ ] No

[ ] Yes

34.6. Allergy

[ ] No

[ ] Yes

34.7. Diseases of the stomach or intestines

[ ] No

[ ] Yes

34.8. Kidney diseases

[ ] No

[ ] Yes

34.9. Liver diseases

[ ] No

[ ] Yes

34.10. Skin diseases

[ ] No

[ ] Yes

34.11. Psychiatric problems

[ ] No

[ ] Yes

34.12. Blood diseases

[ ] No

[ ] Yes

34.13. Diseases of the thyroid gland

[ ] No

[ ] Yes

34.14. Please describe your disease(s):

_____

_____

_____

_____

35. Please indicate if you suffer from one or more of the following autoimmune diseases:

35.1. Rheumatoid arthritis (rheumatism)

[ ] No

[ ] Yes

35.2. Inflammatory bowel disease (Crohn’s disease/colitis ulcerosa)

[ ] No

[ ] Yes

35.3. Lupus erythematosus

[ ] No

[ ] Yes

35.4. Psoriasis

[ ] No

[ ] Yes

35.5. Wegener's granulomatosis

[ ] No

[ ] Yes

35.6. Vasculitis

[ ] No

[ ] Yes

35.7. Nephritis

[ ] No

[ ] Yes

35.8. Hashimoto thyroiditis

[ ] No

[ ] Yes

35.9. Cogan's syndrome

[ ] No

[ ] Yes

35.10. Behcet’s syndrome

[ ] No

[ ] Yes

35.11. Other autoimmune diseases:

_____

_____

36. Have you ever had other operations (not covered by the previous questions)?

[ ] No

[ ] Yes: (Please list any operations you have had and the year they were performed)

36.1.

_____ in:_____

36.2.

_____ in:_____

36.3.

_____ in:_____

36.4.

_____ in:_____

36.1.

_____ in:_____

37. Do you have other serious health problems that are not covered by the previous questions?

[ ] No

[ ] Yes

If “YES,”

37.1. Please describe these problems:

_____

Medication

38. Have you ever been treated for a serious infection with an antibiotic (other than penicillin) which was administered by injection/drip for a week or more?

[ ] No

[ ] Yes

38.1. If “YES,” for what sort of infections did you receive these antibiotics?

_____

38.2. In which year(s) approximately?_____

39. Have you had cancer or leukemia?

[ ] No

[ ] Yes

If “YES,”

39.1. Which kind of cancer or leukemia?

_____

39.2. Have you been treated with chemotherapy or other medication for this condition?

[ ] No

[ ] Yes

39.3 If “YES,” with_____
(please fill in which medication if you know it)

39.3 in _____ (in which year(s) approximately)

40. Have you ever received radiotherapy to your head or neck for a tumour?

[ ] No

[ ] Yes

If “YES,”

40.1. What kind of tumour(s)? _____

40.2. In which year(s) approximately? _____

41. On average how often do you take painkillers?

[ ] never

[ ] less than 1 tablet a month

[ ] less than 1 tablet a week (but more than one each month)

2 [ ]–5 tablets a week

2 [ ]–5 tablets a day

[ ] more than 5 tablets a day

42. Do you take aspirin on a daily basis for your heart or to dilute your blood?

[ ] No

[ ] Yes

42.1. If “YES,” how long have you been taking aspirin so far?

3 [ ] months–1 year

1 [ ]–5 years

[ ] more than 5 years

43. Please list all of the medication you have taken on a regular basis (for more than 3 months) in the last year or that you are taking now on a regular basis.

Please write down the medical reason why you had or have to take this medication. If necessary, you can add an additional copy of this page.

43.1. Name drug: _____

43.2. Medical reason: _____

43.3. Duration of treatment

3 [ ] months–1 year

1 [ ]–5 years

[ ] more than 5 years

43.4. Name drug: _____

43.5. Medical reason: _____

43.6. Duration of treatment

3 [ ] months–1 year

1 [ ]–5 years

[ ] more than 5 years

43.7. Name drug: _____

43.8. Medical reason: _____

43.9. Duration of treatment

3 [ ] months–1 year

1 [ ]–5 years

[ ] more than 5 years

43.10. Name drug: _____

43.11. Medical reason: _____

43.12. Duration of treatment

3 [ ] months–1 year

1 [ ]–5 years

[ ] more than 5 years

43.13. Name drug: _____

43.14. Medical reason: _____

43.15. Duration of treatment

3 [ ] months–1 year

1 [ ]–5 years

[ ] more than 5 years

43.16. Name drug: _____

43.17. Medical reason: _____

43.18. Duration of treatment

3 [ ] months–1 year

1 [ ]–5 years

[ ] more than 5 years

43.19. Name drug: _____

43.20. Medical reason: _____

43.21. Duration of treatment

3 [ ] months–1 year

1 [ ]–5 years

[ ] more than 5 years

43.22. Name drug: _____

43.23. Medical reason: _____

43.24. Duration of treatment

3 [ ] months–1 year

1 [ ]–5 years

[ ] more than 5 years

43.25. Name drug: _____

43.26. Medical reason: _____

43.27. Duration of treatment

3 [ ] months–1 year

1 [ ]–5 years

[ ] more than 5 years

43.28. Name drug: _____

43.29. Medical reason: _____

43.30. Duration of treatment

3 [ ] months–1 year

1 [ ]–5 years

[ ] more than 5 years

Noise Exposure

44. Have you ever fired a gun?

[ ] No

[ ] Yes

If “YES,” please answer the following questions.

Type of weapon	44.1. Estimate the total number of shots fired	44.2. Did you use ear protection?	44.3. If any, which type of ear protection did you use?
Light weapons (rifles/shotguns)	[ ] less than 10 shots [ ] 10–100 shots [ ] 101–1,000 shots [ ] 1,001–10,000 shots [ ] more than 10,000 shots	[ ] always [ ] most of the time [ ] more than 50% of the time [ ] less than 50% of the time [ ] never	[ ] plugs [ ] earmuff [ ] “active” protection [ ] several
Heavy weapons (artillery/bazookas)	[ ] less than 10 shots [ ] 10–100 shots [ ] 101–1,000 shots [ ] 1,001–10,000 shots [ ] more than 10,000 shots	[ ] always [ ] most of the time [ ] more than 50% of the time [ ] less than 50% of the time [ ] never	[ ] plugs [ ] earmuff [ ] “active” protection [ ] several

45. During your leisure time, are you/have you been regularly (more than once a week) exposed to loud sound or noise (so that you have to shout to make yourself heard by someone who was more than 1 m away from you)?

[ ] No

[ ] Yes

If you answered “YES,” please also answer the following questions (44.1–44.5).

45.1. What kind of loud sound? _____

45.2. For how many years have you been exposed to this loud sound?
_____

45.3. How many hours per week have you been exposed to this loud sound?

1 [ ]–3 hours each week

3 [ ]–10 hours each week

1 [ ]–3 hours each day

[ ] More than 3 hours each day

45.4. Did you use ear protection?

[ ] Always

[ ] Most of the time

[ ] More than 50% of the time

[ ] Less than 50% of the time

[ ] Never

45.5. If any, which type of ear protection did you use?

[ ] Plugs

[ ] Earmuff

[ ] “Active” protection

[ ] Several

Occupational Information

46. What is/was your job?

_____

47. Have you been exposed to solvents (e.g., thrichloroethylene, toluene, evaporations from paints or lacquers) for more than one year in one of your jobs?

[ ] No

[ ] Yes

If “YES,”

47.1. Which solvents?

_____

47.2. In which year did the solvent exposure start? _____

47.3. For how many years were you exposed to solvents? _____

47.4. For how many hours per day were you exposed to solvents?

[ ] Less than 1 hour each day

1 [ ]–5 hours each day

[ ] More than 5 hours each day

48. Do you suffer from white finger syndrome/Raynaud's syndrome caused by excessive vibration (e.g., pneumatic hammers or drills)?

[ ] No

[ ] I don’t know

[ ] Yes

49. Have you ever worked for more than 1 year in a place where you had to raise your voice to make yourself heard by someone standing 1 m away from you?

[ ] No

[ ] Yes

If you answered “YES,” please also answer the following questions (48.1–48.10). If you have worked for different companies, or for the same company but in different workplaces (with a different noise level), please fill in the following questions for each “job.”

1st job (add additional copies for other jobs if necessary)

49.1. Please describe the job and give the name of the company

_____

49.2. Please describe the most important noise source(s)

_____

49.3. In which year did you start to do this job? _____

49.4. How many years have you been doing this job? _____

49.5. What was the noise level (if you are aware of it) in dB? _____

49.6. What was the noise dose (equivalent noise level if you are aware of it) in dBs? _____

49.7. How many hours per day were you exposed to noise?

[ ] Less than 1 hour each day

1 [ ]–5 hours each day

[ ] More than 5 hours each day

49.8. Was this a constant loud noise or an impulse noise (i.e., noise with (ir)regular high peaks of sound, like hammering)?

[ ] Constant noise

[ ] Impulse noise

[ ] Both

49.9. Did you use noise protection?

[ ] Always

[ ] Most of the time

[ ] More than 50% of the time

[ ] Less than 50% of the time

[ ] Never

49.10. If any, which type of noise protection did you use?

[ ] Plugs

[ ] Earmuff

[ ] “Active” protection

[ ] Several

Background Information

50. What is your height? _____cm (feet and inches)

51. What is your weight? _____kg (stones and pounds)

52. Are you left or right handed?

[ ] left handed

[ ] right handed

53. Are you susceptible to sunburn?

[ ] very much

[ ] much

[ ] not very much

[ ] not at all

54. What is the color of your eyes?

[ ] very light blue or very light grey

[ ] blue

[ ] grey

[ ] green

[ ] light brown

[ ] dark brown

55. Have you ever smoked regularly?

[ ] No

[ ] Yes

If you answered “Yes,” please also answer the following questions (54.1–54.5).

55.1. At which age did you start smoking? _____

55.2. For how many years did you (have you) smoke(d) up to now? _____

55.3. Approximately how many cigarettes do (did) you smoke on average?

[ ] Less than 5 each day

5 [ ]–10 each day

10 [ ]–20 each day

[ ] More than 20 each day

55.4. Approximately how many cigars or cigarillos do (did) you smoke on average each day? _____

55.5. Approximately how much pipe tobacco (grams) do (did) you smoke each day?

_____

56. Do you drink alcohol regularly (every week)?

[ ] No

[ ] Yes

If “YES,”

57.1. How many drinks do you have on average? (A small bottle of beer – 25cl, red or white wine – 12cl, or a small glass of spirits – 4cl counts as 1 drink).

[ ] Less than 1 drink each week

1 [ ]–5 drinks each week

1 [ ]–3 drinks each day

[ ] More than 3 drinks each day

Scoring Instructions

Please see Fransen et al. (2008) for a complete description of the statistical analysis used for these questions. Also, supplementary table 4 contains information on how the different variables were coded in this statistical analysis.

Protocol source: https://www.phenxtoolkit.org/protocols/view/201501