

## Data Collection Worksheet

**Please Note:** The Data Collection Worksheet (DCW) is a tool to aid investigators to integrate the collection of PhenX measures in your study. The PhenX measures that you selected and added to your Cart are presented in the DCW in alphabetical order. The DCW includes worksheets for data collection. Variables derived from the collected data are shown in the Data Dictionary (DD) with variable names and unique PhenX variable identifiers. The collection of DCWs produced by the Toolkit is not designed as a data collection instrument. Each investigator will decide how to integrate PhenX measures into data collection for their study.

Before beginning the taste and smell exams, the individual will be asked a short series of questions to screen him or her for exclusion criteria and then additional questions are asked to identify any conditions he or she may currently have, such as a head cold or sinus problem, that may alter or influence the interpretation of the exam results at the time it is performed. The questions are as follows:

1. Are you currently pregnant or breastfeeding a baby?
2. Today, do you have any of the following problems with your nose? Mark all that apply. ?
  - Sneeze frequently;
  - Green, yellow, or brown mucus discharge;
  - Completely blocked-up nose;
  - Sinus pain; or
  - A head cold or runny nose from the flu.
3. Is your nose blocked-up on both sides, or on just one side?

If the individual answers "Yes," "Don't Know," or "Refused" to questions 2, she will be excluded from the entire exam.

(INTERVIEWER INSTRUCTION: Blocked up nose is when you can't breathe air in and out of the nose. Sinus pain is pain, pressure or fullness in the area of the face behind the cheeks or forehead.)

The smell test does not require a formal, standard script. However, the examiner will provide a brief introduction to the examination using the following talking points provided (Appendix B):

- Purpose - To see how well you can identify some common smells
- Two cards:
  - Each card has 4 smells;
  - Each smell has 4 choices;
  - Look at the four choices while I read them to you; and

- Tell me which choice is what you smelled.
- If not sure, pick the closest; and
- If no smell, guess.

Open the first card and show the individual the different scent strips. Explain that you will scratch the brown rectangle left to right in a "z" pattern to properly release the test odor. The Modified Pocket Smell Test should be folded one page at a time as the health techs (HTs) proceed with the test. This is done so that individuals' only smell one scent of the booklet at a time, and not previously scratched odors as well. After scratching the scent strip, ask the individual to hold the card under his or her nose and sniff the odor. The individual should be encouraged to sniff the label immediately after it has been scratched to ensure that the odor has not significantly dissipated. Ask the individual to identify the scent after reading all answer choices from the computer screen, and record the individual's answer on the application.

In order for the test to be valid, you must read all the answer choices even if the individual selects one right away. This is especially important in situations where the correct response might be the first choice. If the odor the individual smells is not represented by one of the four choices provided, the individual needs to choose the answer closest to his or her experience. If the individual smells nothing, he or she must guess the best answer.

The M-PST is designed as a forced-choice test, so it is essential that individuals choose one of the four possible responses even if they smell nothing at all. The overall test score can't be calculated unless all eight items are completed. It is known that people with loss of smell may have some remaining ability to smell even if they are not aware of it. This is the reason for prompting them to guess an answer even if they believe they smell nothing. The M-PST is scored by the overall number of items that are correctly identified so there must be an answer for each test scent for the test to be valid.

Once the individual has completed one scent, go immediately to the next scent, and so on, until all eight odorants are completed. There is no need to pause or wait between scents. In some cases, the individual's may request HTs to re-scratch an odor strip. In most cases, it is unnecessary and does not help with identification. The odorants are as follows:

#### M-PST Items:

- Chocolate
- Strawberry
- Smoke
- Leather
- Soap
- Grape
- Onion
- Natural Gas

This section includes one screen per odor and will contain a place to indicate what the odor smells most. Please choose one of the four alternative smells from each screen.

Item 1

The odor smells most like

- Lemon
- Chocolate
- Smoke
- Black Pepper

Item 2

The odor smells most like

- Strawberry
- Garlic
- Leather
- Gasoline

Item 3

The odor smells most like

- Garlic
- Grass
- Smoke
- Peach

Item 4

The odor smells most like

- Mint
- A flower
- Leather
- Apple

Item 5

The odor smells most like

- Soap
- Black Pepper
- Leather
- Peanut

Item 6

The odor smells most like

- Gasoline
- Grape
- Rose
- Peanut

Item 7

The odor smells most like

- Chocolate
- Strawberry
- Onion
- Fruit Punch

Item 8

The odor smells most like

- Orange
- Cinnamon
- Cola
- Natural Gas

Participant Evaluation

This section is to provide information to help determine if the individual had any problems with the entire exam.

Rate the individual's overall understanding of the entire test as very good, good, fair, poor, or unable to cooperate. \_\_\_\_\_

Additional Smell and Taste Questions

1. The next questions are about {your/SP's} sense of smell. During the past 12 months, {have you/has he/has she} had a problem with {your/his/her} ability to smell, such as not being able to smell things or things not smelling the way they are supposed to?

- 1  YES
- 2  NO
- 7  REFUSED
- 9  DON'T KNOW

2. How would {you/SP} rate {your/his/her} ability to smell now as compared to when {you were/he was/she was} 25 years old? Is it better, worse or is there no change?

- 1  BETTER NOW
- 2  WORSE NOW
- 3  NO CHANGE
- 7  REFUSED
- 9  DON'T KNOW

3. Do some smells bother {you/SP} although they do not bother other people?

- 1  YES
- 2  NO
- 7  REFUSED
- 9  DON'T KNOW

4. {Do you/Does SP} sometimes smell an unpleasant, bad or burning odor when nothing is there?

- 1  YES
- 2  NO
- 7  REFUSED
- 9  DON'T KNOW

IF Q.1 = 1 OR Q.2 = 2 OR Q.4 = 1, THEN CONTINUE, OTHERWISE, GO TO Q.6.

5. Is the problem with {your/SP's} ability to smell always there or does it come and go?

INTERVIEWER INSTRUCTION: PLEASE INCLUDE TEMPORARY PROBLEMS WITH THE SP'S SENSE OF SMELL DUE TO ALLERGIES BUT DO NOT INCLUDE ANY PROBLEMS WITH SMELL DUE TO A HEAD COLD.

- 1  IT IS ALWAYS THERE ..... 1
- 2  IT COMES AND GOES..... 2
- 3  I HAVE A PROBLEM ONLY WITH A COLD ..... 3
- 7  REFUSED..... 7
- 9  DON'T KNOW..... 9

CAPI INSTRUCTION:

DISPLAY REASON GOT TO THIS QUESTION ABOVE QUESTION TEXT FOR INTERVIEWER REFERENCE.

IF Q.2 = 2 DISPLAY "SMELL WORSE THAN WHEN 25"

IF Q.4 = 1 DISPLAY "SMELL ODOR WHEN NOT THERE"

6. The next questions are about {your/SP's} sense of taste. During the past 12 months, {have you/has he/has she} had a problem with {your/his/her} ability to taste sweet, sour, salty or bitter foods and drinks?

- 1  YES
- 2  NO
- 7  REFUSED
- 9  DON'T KNOW

7. I am going to read you a list of tastes in everyday foods. How {is your/is SP's} ability to taste each one of these now compared to when {you were/he was/she was} 25 years old? Would you say it is better, worse, or is there no change?

INTERVIEWER INSTRUCTION: PLEASE DO NOT INCLUDE TEMPORARY PROBLEMS WITH THE SPs SENSE OF SMELL DUE TO A HEAD COLD.

RESPONSES: BETTER = 1, WORSE = 2, NO CHANGE = 3, REFUSED = 7, DON'T KNOW = 9

a. salt in foods like potato chips or pretzels

- 1  Better
- 2  Worse
- 3  No Change
- 7  Refused
- 9  Don't Know

b. sourness in foods like lemons or vinegar

- 1  Better
- 2  Worse
- 3  No Change
- 7  Refused
- 9  Don't Know

c. sweetness in foods like peaches or ice cream

- 1  Better
- 2  Worse
- 3  No Change
- 7  Refused
- 9  Don't Know

d. bitterness in drinks like unsweetened black coffee

- 1  Better
- 2  Worse
- 3  No Change
- 7  Refused
- 9  Don't Know

8. Is {your/SP's} ability to taste food flavors such as chocolate, vanilla or strawberry as good as when {you were/he was/she was} 25 years old?

- 1  YES
- 2  NO
- 7  REFUSED
- 9  DON'T KNOW

9. During the past 12 months {have you/has SP} had a taste or other sensation in {your/his/her} mouth that does not go away?

- 1  YES
- 2  NO
- 7  REFUSED
- 9  DON'T KNOW

IF Q.6 = 1 OR Q.7 (ANY) = 2 OR Q.8 = 2 OR Q.9 = 1, THEN CONTINUE, OTHERWISE, GO TO END

10. Please describe the taste or other sensation in {your/SP's} mouth that does not go away.  
Would {you/he/she} say it is:

CODE ALL THAT APPLY.

- 1  sweet
- 2  sour
- 3  salty
- 4  bitter
- 5  metallic
- 6  burning or tingling
- 7  bad or foul
- 8  or something else
- 77  REFUSED
- 99  DON'T KNOW

11. During the past 12 months, {have you/has SP} experienced a problem with {your/his/her} general health, work or {your/his/her} enjoyment of life because of a problem with {your/his/her} ability to taste or smell?

INTERVIEWER INSTRUCTION: INCLUDE PROBLEMS WITH DIET AND WEIGHT AS HEALTH PROBLEMS.

- 1  YES
- 2  NO
- 7  REFUSED
- 9  DON'T KNOW

Protocol source: <https://www.phenxtoolkit.org/protocols/view/251501#Source>