



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.

Administration Instructions:

Participants should answer all the questions as if the participant is wearing his/her glasses or contact lenses (if any).

An Appendix of additional questions may be added to address other sub-scales of vision-targeted health-related quality of life. For example, if a user is testing a new treatment for macular degeneration, by adding near vision questions A3, A4, and A5 to VFQ-25 questions 5, 6, and 7, the investigator would have a six-item near vision scale rather than a three-item scale. The addition of these items would enhance the reliability of the near vision sub-scale and is likely to improve the responsiveness of the sub-scale to the intervention over time. If items from the appendix are used, the VFQ-25 developers encourage users to incorporate all optional items for a given sub-scale. This strategy will enhance the comparability of results across studies.

Skip Question 1 when the VFQ-25 is administered at the same time as the SF-36 or RAND 36-Item Health Survey 1.0

PART 1- GENERAL HEALTH AND VISION

1. In general, would you say your overall health is:

1 excellent

2 very good

3 good

4 fair

5 poor

2. At the present time, would you say your eyesight using both eyes (with glasses or contact lenses, if you wear them) is excellent, good, fair, poor, or very poor or are you completely blind?

- 1 [] excellent
- 2 [] good
- 3 [] fair
- 4 [] poor
- 5 [] very poor
- 6 [] completely blind

3. How much of the time do you worry about your eyesight?

- 1 [] none of the time
- 2 [] a little of the time
- 3 [] some of the time
- 4 [] most of the time
- 5 [] all of the time

4. How much pain or discomfort have you had in and around your eyes (for example, burning, itching, or aching)? Would you say it is:

- 1 [] none
- 2 [] mild
- 3 [] moderate
- 4 [] severe
- 5 [] very severe

PART 2- DIFFICULTY WITH ACTIVITIES

The next questions are about how much difficulty, if any, you have doing certain activities wearing your glasses or contact lenses if you use them for that activity.

5. How much difficulty do you have reading ordinary print in newspapers? Would you say you have:

- 1 [] no difficulty at all
- 2 [] a little difficulty
- 3 [] moderate difficulty
- 4 [] extreme difficulty

5 stopped doing this because of your eyesight

6 stopped doing this for other reasons or not interested in doing this

6. How much difficulty do you have doing work or hobbies that require you to see well up close, such as cooking, sewing, fixing things around the house, or using hand tools? Would you say:

1 no difficulty at all

2 a little difficulty

3 moderate difficulty

4 extreme difficulty

5 stopped doing this because of your eyesight

6 stopped doing this for other reasons or not interested in doing this

7. Because of your eyesight, how much difficulty do you have finding something on a crowded shelf?

1 no difficulty at all

2 a little difficulty

3 moderate difficulty

4 extreme difficulty

5 stopped doing this because of your eyesight

6 stopped doing this for other reasons or not interested in doing this

8. How much difficulty do you have reading street signs or the names of stores?

1 no difficulty at all

2 a little difficulty

3 moderate difficulty

4 extreme difficulty

5 stopped doing this because of your eyesight

6 stopped doing this for other reasons or not interested in doing this

9. Because of your eyesight, how much difficulty do you have going down steps, stairs, or curbs in dim light or at night?

- 1 [] no difficulty at all
- 2 [] a little difficulty
- 3 [] moderate difficulty
- 4 [] extreme difficulty
- 5 [] stopped doing this because of your eyesight
- 6 [] stopped doing this for other reasons or not interested in doing this

10. Because of your eyesight, how much difficulty do you have noticing objects off to the side while you are walking along?

- 1 [] no difficulty at all
- 2 [] a little difficulty
- 3 [] moderate difficulty
- 4 [] extreme difficulty
- 5 [] stopped doing this because of your eyesight
- 6 [] stopped doing this for other reasons or not interested in doing this

11. Because of your eyesight, how much difficulty do you have seeing how people react to things you say?

- 1 [] no difficulty at all
- 2 [] a little difficulty
- 3 [] moderate difficulty
- 4 [] extreme difficulty
- 5 [] stopped doing this because of your eyesight
- 6 [] stopped doing this for other reasons or not interested in doing this

12. Because of your eyesight, how much difficulty do you have picking out and matching your own clothes?

- 1 [] no difficulty at all
- 2 [] a little difficulty
- 3 [] moderate difficulty
- 4 [] extreme difficulty

5 stopped doing this because of your eyesight

6 stopped doing this for other reasons or not interested in doing this

13. Because of your eyesight, how much difficulty do you have visiting with people in their homes, at parties, or in restaurants?

1 no difficulty at all

2 a little difficulty

3 moderate difficulty

4 extreme difficulty

5 stopped doing this because of your eyesight

6 stopped doing this for other reasons or not interested in doing this

14. Because of your eyesight, how much difficulty do you have going out to see movies, plays, or sports events?

1 no difficulty at all

2 a little difficulty

3 moderate difficulty

4 extreme difficulty

5 stopped doing this because of your eyesight

6 stopped doing this for other reasons or not interested in doing this

15. Now, I'd like to ask about driving a car. Are you currently driving, at least once in a while?

1 yes (skip to Q15c)

2 no

15a. IF NO, ASK: Have you never driven a car or have you given up driving?

1 never drove (skip to Part 3, Q17)

2 gave up

15b. IF GAVE UP DRIVING: Was that mainly because of your eyesight, mainly for some other reason, or because of both your eyesight and other reasons?

1 mainly eyesight (skip to Part 3, Q17)

2 [] mainly other reasons (skip to Part 3, Q17)

3 [] both eyesight and other reasons (skip to Part 3, Q17)

15c. IF CURRENTLY DRIVING: How much difficulty do you have driving during the daytime in familiar places? Would you say you have:

1 [] no difficulty at all

2 [] a little difficulty

3 [] moderate difficulty

4 [] extreme difficulty

16. How much difficulty do you have driving at night? Would you say you have:

1 [] no difficulty at all

2 [] a little difficulty

3 [] moderate difficulty

4 [] extreme difficulty

5 [] stopped doing this because of your eyesight

6 [] stopped doing this for other reasons or not interested in doing this

16a. How much difficulty do you have driving in difficult conditions, such as in bad weather, during rush hour, on the freeway, or in city traffic? Would you say you have:

1 [] no difficulty at all

2 [] a little difficulty

3 [] moderate difficulty

4 [] extreme difficulty

5 [] stopped doing this because of your eyesight

6 [] stopped doing this for other reasons or not interested in doing this

PART 3: RESPONSES TO VISION PROBLEMS

The next questions are about how things you do may be affected by your vision. For each one, I'd like you to tell me if this is true for you all, most, some, a little, or non of the time.

17. Do you accomplish less than you would like because of our vision?

- 1 all of the time
- 2 most of the time
- 3 some of the time
- 4 a little of the time
- 5 none of the time

18. Are you limited in how long you can work or do other activities because of your vision?

- 1 all of the time
- 2 most of the time
- 3 some of the time
- 4 a little of the time
- 5 none of the time

19. How much does pain or discomfort in or around your eyes, for example, burning, itching, or aching, keep you from doing what you'd like to be doing? Would you say:

- 1 all of the time
- 2 most of the time
- 3 some of the time
- 4 a little of the time
- 5 none of the time

For each of the following statements, please tell me if it is definitely true, mostly true, mostly false, or definitely false for you or you are not sure.

20. I stay home most of the time because of my eyesight

- 1 definitely true
- 2 mostly true
- 3 not sure
- 4 mostly false

- 5 [] definitely false
21. I feel frustrated a lot of the time because of my eyesight
- 1 [] definitely true
- 2 [] mostly true
- 3 [] not sure
- 4 [] mostly false
- 5 [] definitely false
22. I have much less control over what I do, because of my eyesight
- 1 [] definitely true
- 2 [] mostly true
- 3 [] not sure
- 4 [] mostly false
- 5 [] definitely false
23. Because of my eyesight, I have to rely too much on what other people tell me
- 1 [] definitely true
- 2 [] mostly true
- 3 [] not sure
- 4 [] mostly false
- 5 [] definitely false
24. I need a lot of help from others because of my eyesight
- 1 [] definitely true
- 2 [] mostly true
- 3 [] not sure
- 4 [] mostly false
- 5 [] definitely false
25. I worry about doing things that will embarrass myself or others, because of my eyesight

- 1 [] definitely true
- 2 [] mostly true
- 3 [] not sure
- 4 [] mostly false
- 5 [] definitely false

Appendix of Optional Additional Questions

SUBSCALE: GENERAL HEALTH

A1. How would you rate your overall health, on a scale where zero is as bad as death and 10 is best possible health?

- 1 []
- 2 []
- 3 []
- 4 []
- 5 []
- 6 []
- 7 []
- 8 []
- 9 []
- 10 []

SUBSCALE: GENERAL VISION

A2. How would you rate your eyesight now (with glasses or contact lens on, if you wear them), on a scale of from 1 to 10, where zero means the worst possible eyesight, as bad or worse than being blind, and 10 means the best possible eyesight?

- 1 []
- 2 []
- 3 []
- 4 []

5 []

6 []

7 []

8 []

9 []

10 []

SUBSCALE: NEAR VISION

A3. Wearing glasses, how much difficulty do you have reading the small print in a telephone book, on a medicine bottle, or on legal forms? Would you say:

1 [] no difficulty at all

2 [] a little difficulty

3 [] moderate difficulty

4 [] extreme difficulty

5 [] stopped doing this because of your eyesight

6 [] stopped doing this for other reasons or not interested in doing this

A4. Because of your eyesight, how much difficulty do you have figuring out whether bills you receive are accurate?

1 [] no difficulty at all

2 [] a little difficulty

3 [] moderate difficulty

4 [] extreme difficulty

5 [] stopped doing this because of your eyesight

6 [] stopped doing this for other reasons or not interested in doing this

A5. Because of your eyesight, how much difficulty do you have doing things like shaving, styling your hair, or putting on makeup?

1 [] no difficulty at all

2 [] a little difficulty

3 [] moderate difficulty

4 [] extreme difficulty

5 [] stopped doing this because of your eyesight

6 [] stopped doing this for other reasons or not interested in doing this

SUBSCALE: DISTANCE VISION

A6. Because of your eyesight, how much difficulty do you have recognizing people you know from across a room?

1 [] no difficulty at all

2 [] a little difficulty

3 [] moderate difficulty

4 [] extreme difficulty

5 [] stopped doing this because of your eyesight

6 [] stopped doing this for other reasons or not interested in doing this

A7. Because of you eyesight, how much difficulty do you have taking part in active sports or other outdoor activities that you enjoy (like golf, bowling, jogging, or walking)?

1 [] no difficulty at all

2 [] a little difficulty

3 [] moderate difficulty

4 [] extreme difficulty

5 [] stopped doing this because of your eyesight

6 [] stopped doing this for other reasons or not interested in doing this

A8. Because of your eyesight, how much difficulty do you have seeing and enjoying programs on TV?

1 [] no difficulty at all

2 [] a little difficulty

3 [] moderate difficulty

4 [] extreme difficulty

5 [] stopped doing this because of your eyesight

6 [] stopped doing this for other reasons or not interested in doing this

SUBSCALE: SOCIAL FUNCTION

A9. Because of your eyesight, how much difficulty do you have entertaining friends and family in your home?

1 [] no difficulty at all

2 [] a little difficulty

3 [] moderate difficulty

4 [] extreme difficulty

5 [] stopped doing this because of your eyesight

6 [] stopped doing this for other reasons or not interested in doing this

SUBSCALE: DRIVING

A10. [This item, "driving in difficult conditions", has been included as item 16a as part of the base set of 25 vision-targeted items.]

SUBSCALE: ROLE LIMITATIONS

A11. The next questions are about things you may do because of your vision. For each item, I'd like you to tell me if this is true for you all, most, some, a little, or none of the time.

a. Do you have more help from others because of your vision?

1 [] all of the time

2 [] most of the time

3 [] some of the time

4 [] a little of the time

5 [] none of the time

b. Are you limited in the kinds of things you can do because of your vision?

1 [] all of the time

2 [] most of the time

3 [] some of the time

4 [] a little of the time

5 [] none of the time

Scoring

Scoring VFQ-25 with or without optional items is a two-step process:

Step 1: original numeric values from the survey are re-coded following the scoring rules outlined in Table 1. All items are scored so that a high score represents better functioning. Each item is then converted to a 0 to 100 scale so that the lowest and highest possible scores are set at 0 and 100 points, respectively. In this format scores represent the achieved percentage of the total possible score, e.g. a score of 50 represents 50% of the highest possible score.

Step 2: items within each sub-scale are averaged together to create the 12 sub-scale scores. Table 2 indicates which items contribute to each specific sub-scale. Items that are left blank (missing data) are not taken into account when calculating the scale scores. Sub-scales with at least one item answered can be used to generate a sub-scale score. Hence, scores represent the average for all items in the subscale that the respondent answered.

Composite Score Calculation

To calculate an overall composite score for the VFQ-25, simply average the vision-targeted subscale scores, excluding the general health rating question. By averaging the sub-scale scores rather than the individual items we have given equal weight to each sub-scale, whereas averaging the items would give more weight to scales with more items.

Table 1. Scoring Key: Recoding of Items

Item Numbers	Change original response category ^(a)	To recoded value of:
1,3,4,15 ^(b)	1	100
	2	75
	3	50
	4	25
	5	0
2	1	100
	2	80
	3	60
	4	40
	5	20
	6	0
5,6,7,8,9,10,11,12,13,14,16,16a A3,A4,A5,A6,A7,A8,A9 ^(c)	1	100
	2	75
	3	50

	4 5 6	25 0 *
17,18,19,20,21,22,23,24,25, A11a,A11b,A12,A13	1 2 3 4 5	0 25 50 75 100
A1,A2	0 to 10	0 to 100

(a) Precoded response choices as printed in the questionnaire.

(b) Item 15c has four-response levels, but is expanded to a five-levels using item 15b.

Note: If 15b=1, then 15c should be recoded to "0"

If 15b=2, then 15c should be recoded to missing.

If 15b=3, then 15c should be recoded to missing.

(c) "A" before the item number indicates that this item is an optional item from the Appendix. If optional items are used, the NEI-VFQ developers encourage users to use all items for a given sub-scale. This will greatly enhance the comparability of sub-scale scores across studies.

* Response choice "6" indicates that the person does not perform the activity because of non-vision related problems. If this choice is selected, the item is coded as "missing."

Table 2. Step 2: Averaging of Items to Generate VFQ-25 Sub-Scales

Scale	Number of Items	Items to be averaged (after recoding per Table 1)
General Health	1	1
General Vision	1	2
Ocular Pain	2	4, 19
Near Activities	3	5, 6, 7
Distance Activities	3	8, 9, 14
Vision Specific:		
Social Functioning	2	11, 13
Mental Health	4	3, 21, 22, 25
Role Difficulties	2	17, 18
Dependency	3	20, 23, 24
Driving	3	15c, 16, 16a
Color Vision	1	12
Peripheral Vision	1	10

Table 3. Step 2: Averaging of Items to Generate VFQ-39 Sub-Scales (VFQ-25 + Optional Items)

Scale	Number of Items	Items to be averaged (after recoding per Table 1)
General Health	2	1, A1

General Vision	2	2, A2
Ocular Pain	2	4, 19
Near Activities	6	5, 6, 7, A3, A4, A5
Distance Activities	6	8, 9, 14, A6, A7, A8
Vision Specific:	3	11, 13, A9
Social Functioning	5	3, 21, 22, 25, A12
Mental Health	4	17, 18, A11a, A11b
Role Difficulties	4	20, 23, 24, A13
Dependency		
Driving	3	15c, 16, 16a
Color Vision	1	12
Peripheral Vision	1	10

Protocol source: <https://www.phenxtoolkit.org/protocols/view/111201>