



## 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.

Now we want you to remember what Rs FIRST NAME was like two years ago and to compare it with what [he/she] is like now. Two years ago was in {CURRENT INTERVIEW YEAR - 2}. I will read situations where Rs FIRST NAME has to use [his/her] memory or intelligence and we would like you to indicate whether this has improved, stayed the same, or gotten worse in that situation over the past two years.

Note the importance of comparing [his/her] present performance with two years ago. So if two years ago Rs FIRST NAME always forgot where [he/she] had left things, and [he/she] still does, then this would be considered "not much change."

Now we want you to remember what Rs FIRST NAME was like [when we interviewed [him/her] in Rs LAST INTERVIEW MONTH, YEAR /two years ago] and to compare it with what [he/she] was like toward the end of [his/her] life, but leaving out the last month or so of [his/her] life. I will read situations where Rs FIRST NAME had to use [his/her] memory or intelligence and we would like you to indicate whether this had improved, stayed the same, or gotten worse in that situation over that time period.

Note the importance of comparing [his/her] performance toward the end of [his/her] life with [when we interviewed [him/her] in Rs LAST INTERVIEW MONTH, YEAR/two years ago]. So if two years ago Rs FIRST NAME always forgot where [he/she] had left things, and [he/she] still did, then this would be considered "not much change."

1. Compared with two years ago, how is Rs FIRST NAME at:

Remembering things about family and friends, such as occupations, birthdays, and addresses.

Has this improved, not much changed, or gotten worse?

Compared with [when we interviewed [him/her] in Rs LAST IW MONTH, YEAR/two years ago], how was Rs FIRST NAME at:

Remembering things about family and friends, such as occupations, birthdays, and addresses.

Had this improved, not much changed, or gotten worse?

- 1  IMPROVED
- 2  NOT MUCH CHANGED - GO TO Q4
- 3  GOTTEN WORSE - GO TO Q3
- 4  DOES NOT APPLY; R DOESNT DO ACTIVITY - GO TO Q4
- 8  DK - GO TO Q4
- 9  RF - GO TO Q4

2. Is it much improved or a bit improved?

- 1  MUCH IMPROVED - GO TO Q4
- 2  A BIT IMPROVED - GO TO Q4
- 8  DK - GO TO Q4
- 9  RF - GO TO Q4

3. Is it much worse or a bit worse?

- 4  A BIT WORSE
- 5  MUCH WORSE
- 8  DK
- 9  RF

4. Compared with two years ago, how is Rs FIRST NAME at:

Remembering things that have happened recently?

(Has this improved, not much changed, or gotten worse?)

Compared with [when we interviewed [him/her] in Rs LAST INTERVIEW MONTH, YEAR/two years ago], how was Rs FIRST NAME at:

Remembering things that had happened recently?

(Had this improved, not much changed, or gotten worse?)

- 1  IMPROVED

2 [ ] NOT MUCH CHANGED - GO TO Q7

3 [ ] GOTTEN WORSE- GO TO Q6

4 [ ] DOES NOT APPLY; R DOESNT DO ACTIVITY - GO TO Q7

8 [ ] DK - GO TO Q7

9 [ ] RF - GO TO Q7

5. Is it much improved or a bit improved?

1 [ ] MUCH IMPROVED

2 [ ] A BIT IMPROVED

8 [ ] DK

9 [ ] RF

GO TO Q7

6. Is it much worse or a bit worse?

4 [ ] A BIT WORSE

5 [ ] MUCH WORSE

8 [ ] DK

9 [ ] RF

7. (Compared with two years ago, how is Rs FIRST NAME at:)

Recalling conversations a few days later?

(Has this improved, not much changed, or gotten worse?)

(Compared with [when we interviewed [him/her] in Rs LAST INTERVIEW MONTH, YEAR/two years ago], how was Rs FIRST NAME at:)

Recalling conversations a few days later?

(Had this improved, not much changed, or gotten worse?)

1 [ ] IMPROVED

2 [ ] NOT MUCH CHANGED - GO TO Q10

3 [ ] GOTTEN WORSE - GO TO Q9

4 [ ] DOES NOT APPLY; R DOESNT DO ACTIVITY - GO TO Q10

8 [ ] DK - GO TO Q10

9 [ ] RF - GO TO Q10

8. Is it much improved or a bit improved?

1 [ ] MUCH IMPROVED

2 [ ] A BIT IMPROVED

8 [ ] DK

9 [ ] RF

GO TO Q10

9. Is it much worse or a bit worse?

4 [ ] A BIT WORSE

5 [ ] MUCH WORSE

8 [ ] DK

9 [ ] RF

10. (Compared with two years ago, how is Rs FIRST NAME at:)

Remembering [his/her] address and telephone number?

(Has this improved, not much changed, or gotten worse?)

(Compared with [when we interviewed [him/her] in Rs LAST INTERVIEW MONTH, YEAR/two years ago], how was Rs FIRST NAME at:)

Remembering [his/her] address and telephone number?

(Had this improved, not much changed, or gotten worse?)

1 [ ] IMPROVED

2 [ ] NOT MUCH CHANGED - GO TO Q13

3 [ ] GOTTEN WORSE- GO TO Q12

4 [ ] DOES NOT APPLY; R DOESNT DO ACTIVITY - GO TO Q13

8 [ ] DK - GO TO Q13

9 [ ] RF - GO TO Q13

11. Is it much improved or a bit improved?

1 [ ] MUCH IMPROVED

2 [ ] A BIT IMPROVED

8 [ ] DK

9 [ ] RF

GO TO Q13

12. Is it much worse or a bit worse?

4 [ ] A BIT WORSE

5 [ ] MUCH WORSE

8 [ ] DK

9 [ ] RF

13. (Compared with two years ago, how is Rs FIRST NAME at:)

Remembering what day and month it is?

(Has this improved, not much changed, or gotten worse?)

(Compared with [when we interviewed [him/her] in Rs LAST INTERVIEW MONTH, YEAR/two years ago], how was Rs FIRST NAME at:)

Remembering what day and month it was?

(Had this improved, not much changed, or gotten worse?)

1 [ ] IMPROVED

2 [ ] NOT MUCH CHANGED - GO TO Q16

3 [ ] GOTTEN WORSE - GO TO Q15

4 [ ] DOES NOT APPLY; R DOESNT DO ACTIVITY - GO TO Q16

8 [ ] DK - GO TO Q16

9 [ ] RF - GO TO Q16

14. Is it much improved or a bit improved?

1 [ ] MUCH IMPROVED

2 [ ] A BIT IMPROVED

8 [ ] DK

9 [ ] RF

GO TO Q16

15. Is it much worse or a bit worse?

4 [ ] A BIT WORSE

5 [ ] MUCH WORSE

8 [ ] DK

9 [ ] RF

16. (Compared with two years ago, how is Rs FIRST NAME at:)

Remembering where things are usually kept?

(Has this improved, not much changed, or gotten worse?)

(Compared with [when we interviewed [him/her] in Rs LAST INTERVIEW MONTH, YEAR/two years ago], how was Rs FIRST NAME at:)

Remembering where things were usually kept?

(Had this improved, not much changed, or gotten worse?)

1 [ ] IMPROVED

2 [ ] NOT MUCH CHANGED - GO TO Q19

3 [ ] GOTTEN WORSE - GO TO Q18

4 [ ] DOES NOT APPLY; R DOESNT DO ACTIVITY - GO TO Q19

8 [ ] DK - GO TO Q19

9 [ ] RF - GO TO Q19

17. Is it much improved or a bit improved?

1 [ ] MUCH IMPROVED

2 [ ] A BIT IMPROVED

GO TO Q19

18. Is it much worse or a bit worse?

4  A BIT WORSE

5  MUCH WORSE

8  DK

9  RF

19. (Compared with two years ago, how is Rs FIRST NAME at:)

Remembering where to find things which have been put in a different place than usual?

(Has this improved, not much changed, or gotten worse?)

(Compared with [when we interviewed [him/her] in Rs LAST INTERVIEW MONTH, YEAR/two years ago], how was Rs FIRST NAME at:)

Remembering where to find things which had been put in a different place than usual?

(Had this improved, not much changed, or gotten worse?)

1  IMPROVED

2  NOT MUCH CHANGED - GO TO Q22

3  GOTTEN WORSE - GO TO Q21

4  DOES NOT APPLY; R DOESNT DO ACTIVITY - GO TO Q22

8  DK - GO TO Q22

9  RF - GO TO Q22

20. Is it much improved or a bit improved?

1  MUCH IMPROVED

2  A BIT IMPROVED

8  DK

9  RF

GO TO Q22

21. Is it much worse or a bit worse?

4  A BIT WORSE

5  MUCH WORSE

8  DK

9  RF

22. (Compared with two years ago, how is Rs FIRST NAME at:)

Knowing how to work familiar machines around the house?

(Has this improved, not much changed, or gotten worse?)

(Compared with [when we interviewed [him/her] in Rs LAST INTERVIEW MONTH, YEAR/two years ago], how was Rs FIRST NAME at:)

Knowing how to work familiar machines around the house?

(Had this improved, not much changed, or gotten worse?)

1  IMPROVED

2  NOT MUCH CHANGED - GO TO Q25

3  GOTTEN WORSE - GO TO Q24

4  DOES NOT APPLY; R DOESNT DO ACTIVITY - GO TO Q25

8  DK - GO TO Q25

9  RF - GO TO Q25

23. Is it much improved or a bit improved?

1  MUCH IMPROVED

2  A BIT IMPROVED

8  DK

9  RF

GO TO Q25

24. Is it much worse or a bit worse?

4  A BIT WORSE



5  MUCH WORSE

8  DK

9  RF

25. (Compared with two years ago, how is Rs FIRST NAME at:)

Learning to use a new gadget or machine around the house?

(Has this improved, not much changed, or gotten worse?)

(Compared with [when we interviewed [him/her] in Rs LAST INTERVIEW MONTH, YEAR/two years ago], how was Rs FIRST NAME at:)

Learning to use a new gadget or machine around the house?

(Had this improved, not much changed, or gotten worse?)

1  IMPROVED

2  NOT MUCH CHANGED - GO TO Q28

3  GOTTEN WORSE - GO TO Q27

4  DOES NOT APPLY; R DOESNT DO ACTIVITY - GO TO Q28

8  DK - GO TO Q28

9  RF - GO TO Q28

26. Is it much improved or a bit improved?

1  MUCH IMPROVED

2  A BIT IMPROVED

8  DK

9  RF

GO TO Q28

27. Is it much worse or a bit worse?

4  A BIT WORSE

5  MUCH WORSE

8  DK

9 [ ] RF

28. (Compared with two years ago, how is Rs FIRST NAME at:)

Learning new things in general?

(Has this improved, not much changed, or gotten worse?)

(Compared with [when we interviewed [him/her] in Rs LAST INTERVIEW MONTH, YEAR/two years ago], how was Rs FIRST NAME at:)

Learning new things in general?

(Had this improved, not much changed, or gotten worse?)

1 [ ] IMPROVED

2 [ ] NOT MUCH CHANGED - GO TO Q31

3 [ ] GOTTEN WORSE - GO TO Q30

4 [ ] DOES NOT APPLY; R DOESNT DO ACTIVITY - GO TO Q31

8 [ ] DK - GO TO Q31

9 [ ] RF - GO TO Q31

29. Is it much improved or a bit improved?

1 [ ] MUCH IMPROVED

2 [ ] A BIT IMPROVED

8 [ ] DK

9 [ ] RF

GO TO Q31

30. Is it much worse or a bit worse?

4 [ ] A BIT WORSE

5 [ ] MUCH WORSE

8 [ ] DK

9 [ ] RF

31. (Compared with two years ago, how is Rs FIRST NAME at:)

Following a story in a book or on TV?

(Has this improved, not much changed, or gotten worse?)

(Compared with [when we interviewed [him/her] in Rs LAST INTERVIEW MONTH, YEAR/two years ago], how was Rs FIRST NAME at:)

Following a story in a book or on TV?

(Had this improved, not much changed, or gotten worse?)

1  IMPROVED

2  NOT MUCH CHANGED - GO TO Q34

3  GOTTEN WORSE - GO TO Q33

4  DOES NOT APPLY; R DOESNT DO ACTIVITY - GO TO Q34

8  DK - GO TO Q34

9  RF - GO TO Q34

32. Is it much improved or a bit improved?

1  MUCH IMPROVED

2  A BIT IMPROVED

8  DK

9  RF

GO TO Q34

33. Is it much worse or a bit worse?

4  A BIT WORSE

5  MUCH WORSE

8  DK

9  RF

34. (Compared with two years ago, how is Rs FIRST NAME at:)

Making decisions on everyday matters?

(Has this improved, not much changed, or gotten worse?)

(Compared with [when we interviewed [him/her] in Rs LAST INTERVIEW MONTH, YEAR/two years ago], how was Rs FIRST NAME at:)

Making decisions on everyday matters?

(Had this improved, not much changed, or gotten worse?)

1  IMPROVED

2  NOT MUCH CHANGED - GO TO Q37

3  GOTTEN WORSE - GO TO Q36

4  DOES NOT APPLY; R DOESNT DO ACTIVITY- GO TO Q37

8  DK - GO TO Q37

9  RF - GO TO Q37

35. Is it much improved or a bit improved?

1  MUCH IMPROVED

2  A BIT IMPROVED

8  DK

9  RF

GO TO Q37

36. Is it much worse or a bit worse?

4  A BIT WORSE

5  MUCH WORSE

8  DK

9  RF

37. (Compared with two years ago, how is Rs FIRST NAME at:)

Handling money for shopping?

(Has this improved, not much changed, or gotten worse?)

(Compared with [when we interviewed [him/her] in Rs LAST INTERVIEW MONTH, YEAR/two years ago], how was Rs FIRST NAME at:)

Handling money for shopping?

(Had this improved, not much changed, or gotten worse?)

1  IMPROVED

2  NOT MUCH CHANGED - GO TO Q40

3  GOTTEN WORSE - GO TO Q439

4  DOES NOT APPLY; R DOESNT DO ACTIVITY - GO TO Q40

8  DK - GO TO Q40

9  RF - GO TO Q40

38. Is it much improved or a bit improved?

1  MUCH IMPROVED

2  A BIT IMPROVED

8  DK

9  RF

GO TO Q40

39. Is it much worse or a bit worse?

4  A BIT WORSE

5  MUCH WORSE

8  DK

9  RF

40. (Compared with two years ago, how is Rs FIRST NAME at:)

Handling financial matters, that is, [his/her] pension or dealing with the bank?

(Has this improved, not much changed, or gotten worse?)

(Compared with [when we interviewed [him/her] in Rs LAST INTERVIEW MONTH, YEAR/two years ago], how was Rs FIRST NAME at:)

Handling financial matters, for example, a pension or dealing with the bank?

(Had this improved, not much changed, or gotten worse?)

1  IMPROVED

2 [ ] NOT MUCH CHANGED - GO TO Q43

3 [ ] GOTTEN WORSE - GO TO Q42

4 [ ] DOES NOT APPLY; R DOESNT DO ACTIVITY - GO TO Q43

8 [ ] DK - GO TO Q43

9 [ ] RF - GO TO Q43

41. Is it much improved or a bit improved?

1 [ ] MUCH IMPROVED

2 [ ] A BIT IMPROVED

8 [ ] DK

9 [ ] RF

GO TO Q43

42. Is it much worse or a bit worse?

4 [ ] A BIT WORSE

5 [ ] MUCH WORSE

8 [ ] DK

9 [ ] RF

43. (Compared with two years ago, how is Rs FIRST NAME at:)

Handling other everyday arithmetic problems, such as knowing how much food to buy, knowing how long between visits from family or friends? (Has this improved, not much changed, or gotten worse?)

(Compared with [when we interviewed [him/her] in Rs LAST INTERVIEW MONTH, YEAR/two years ago], how was Rs FIRST NAME at:)

Handling other everyday arithmetic problems, such as knowing how much food to buy, knowing how long between visits from family or friends? (Had this improved, not much changed, or gotten worse?)

1 [ ] IMPROVED

2 [ ] NOT MUCH CHANGED - GO TO Q46

3 [ ] GOTTEN WORSE - GO TO Q45

4 [ ] DOES NOT APPLY; R DOESNT DO ACTIVITY - GO TO Q46

8 [ ] DK - GO TO Q46

9 [ ] RF - GO TO Q46

44. Is it much improved or a bit improved?

1 [ ] MUCH IMPROVED

2 [ ] A BIT IMPROVED

8 [ ] DK

9 [ ] RF

GO TO Q46

45. Is it much worse or a bit worse?

4 [ ] A BIT WORSE

5 [ ] MUCH WORSE

8 [ ] DK

9 [ ] RF

46. (Compared with two years ago, how is Rs FIRST NAME at:)

Using [his/her] intelligence to understand whats going on and to reason things through?

(Has this improved, not much changed, or gotten worse?)

(Compared with [when we interviewed [him/her] in Rs LAST INTERVIEW MONTH, YEAR/two years ago], how was Rs FIRST NAME at:)

Using [his/her] intelligence to understand what was going on and to reason things through?

(Had this improved, not much changed, or gotten worse?)

1 [ ] IMPROVED

2 [ ] NOT MUCH CHANGED - GO TO Q49

3 [ ] GOTTEN WORSE - GO TO Q48

4 [ ] DOES NOT APPLY; R DOESNT DO ACTIVITY - GO TO Q49

8 [ ] DK - GO TO Q49

9 [ ] RF - GO TO Q49

47. Is it much improved or a bit improved?

1 [ ] MUCH IMPROVED

2 [ ] A BIT IMPROVED

8 [ ] DK

9 [ ] RF

GO TO Q49

48. Is it much worse or a bit worse?

4 [ ] A BIT WORSE

5 [ ] MUCH WORSE

8 [ ] DK

9 [ ] RF

49. Now, thinking about some current behaviors, does [he/she] ever get lost in a familiar environment?

Did [he/she] ever get lost in a familiar environment?

1 [ ] YES

5 [ ] NO

8 [ ] DK

9 [ ] RF

50. Does [he/she] ever wander off and not return by [himself/ herself]?

Did [he/she] ever wander off and not return by [himself/ herself]?

1 [ ] YES

5 [ ] NO

8 [ ] DK

9 [ ] RF

51. Can [he/she] be left alone for an hour or so?



[Since Rs LAST INTERVIEW MONTH, YEAR/In the last two years] could [he/she] be left alone for an hour or so?

1  YES

5  NO

8  DK

9  RF

52. Does [he/she] ever see or hear things that are not really there?

Did Rs FIRST NAME ever see or hear things that were not really there?

1  YES

5  NO

8  DK

9  RF

Protocol source: <https://www.phenxtoolkit.org/protocols/view/250501>