![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.

We are interested in knowing how your experience of having cancer affects your quality of life. Please answer all of the following questions based on your life at this time. Please circle the number from 0 to 10 that best describes your experiences:

Physical Well Being
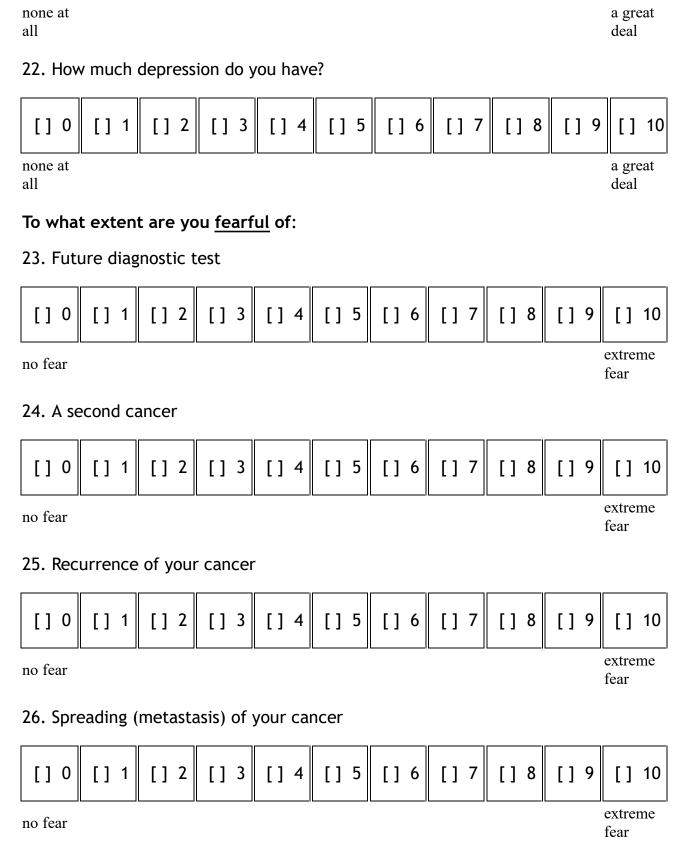
To what extent are the following a problem for you:

1. Fatigue

[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4	[ ] 5	[ ] 6	[ ] 7	[ ] 8	[ ] 9	[ ] 10

no
problem

severe
problem

2. Appetite changes

[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4	[ ] 5	[ ] 6	[ ] 7	[ ] 8	[ ] 9	[ ] 10

no
problem

severe
problem

3. Aches or pain

[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4	[ ] 5	[ ] 6	[ ] 7	[ ] 8	[ ] 9	[ ] 10

no
problem

severe
problem

4. Sleep changes

[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4	[ ] 5	[ ] 6	[ ] 7	[ ] 8	[ ] 9	[ ] 10

no
problem

severe
problem

5. Constipation

[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4	[ ] 5	[ ] 6	[ ] 7	[ ] 8	[ ] 9	[ ] 10

no
problem

severe
problem

6. Nausea

[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4	[ ] 5	[ ] 6	[ ] 7	[ ] 8	[ ] 9	[ ] 10

no
problem

severe
problem

7. Menstrual changes or fertility

[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4	[ ] 5	[ ] 6	[ ] 7	[ ] 8	[ ] 9	[ ] 10

no
problem

severe
problem

8. Rate your overall physical health

[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4	[ ] 5	[ ] 6	[ ] 7	[ ] 8	[ ] 9	[ ] 10

extremely
poor

excellent

Psychological Well Being Items

9. How difficult is it for you to cope as a result of your disease and treatment?

[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4	[ ] 5	[ ] 6	[ ] 7	[ ] 8	[ ] 9	[ ] 10

not at all
difficult

extremely
difficult

10. How good is your quality of life ?

| [ ] 0 | [ ] 1 | [ ] 2 | [ ] 3 | [ ] 4 | [ ] 5 | [ ] 6 | [ ] 7 | [ ] 8 | [ ] 9 | [ ] 10 |

extremely
poor
                                                                                                        excellent

11. How much happiness do you feel?

| [ ] 0 | [ ] 1 | [ ] 2 | [ ] 3 | [ ] 4 | [ ] 5 | [ ] 6 | [ ] 7 | [ ] 8 | [ ] 9 | [ ] 10 |

none at
all
                                                                                                        a great
                                                                                                        deal

12. Do you feel like you are in control of things in your life ?

| [ ] 0 | [ ] 1 | [ ] 2 | [ ] 3 | [ ] 4 | [ ] 5 | [ ] 6 | [ ] 7 | [ ] 8 | [ ] 9 | [ ] 10 |

none at
all
                                                                                                        completely

13. How satisfying is your life ?

| [ ] 0 | [ ] 1 | [ ] 2 | [ ] 3 | [ ] 4 | [ ] 5 | [ ] 6 | [ ] 7 | [ ] 8 | [ ] 9 | [ ] 10 |

none at
all
                                                                                                        completely

14. How is your present ability to concentrate or to remember things?

| [ ] 0 | [ ] 1 | [ ] 2 | [ ] 3 | [ ] 4 | [ ] 5 | [ ] 6 | [ ] 7 | [ ] 8 | [ ] 9 | [ ] 10 |

extremely
poor
                                                                                                        excellent

15. How useful do you feel?

| [ ] 0 | [ ] 1 | [ ] 2 | [ ] 3 | [ ] 4 | [ ] 5 | [ ] 6 | [ ] 7 | [ ] 8 | [ ] 9 | [ ] 10 |

not at
all
                                                                                                        extremely

16. Has your illness or treatment caused changes in your appearance?

| [ ] 0 | [ ] 1 | [ ] 2 | [ ] 3 | [ ] 4 | [ ] 5 | [ ] 6 | [ ] 7 | [ ] 8 | [ ] 9 | [ ] 10 |

not at
all
                                             extremely

17. Has your illness or treatment caused changes in your self concept (the way you see your self?)

| [ ] 0 | [ ] 1 | [ ] 2 | [ ] 3 | [ ] 4 | [ ] 5 | [ ] 6 | [ ] 7 | [ ] 8 | [ ] 9 | [ ] 10 |

not at
all
                                             extremely

How distressing were the following aspects of your illness and treatment?

18. Initial diagnosis

| [ ] 0 | [ ] 1 | [ ] 2 | [ ] 3 | [ ] 4 | [ ] 5 | [ ] 6 | [ ] 7 | [ ] 8 | [ ] 9 | [ ] 10 |

not at all
distressing
                                             very
distressing

19. Cancer treatments (i.e., chemother apy, radiation, or surgery)

| [ ] 0 | [ ] 1 | [ ] 2 | [ ] 3 | [ ] 4 | [ ] 5 | [ ] 6 | [ ] 7 | [ ] 8 | [ ] 9 | [ ] 10 |

not at all
distressing
                                             very
distressing

20. Time since my treatment was completed

| [ ] 0 | [ ] 1 | [ ] 2 | [ ] 3 | [ ] 4 | [ ] 5 | [ ] 6 | [ ] 7 | [ ] 8 | [ ] 9 | [ ] 10 |

not at all
distressing
                                             very
distressing

21. How much anxiety do you have?

| [ ] 0 | [ ] 1 | [ ] 2 | [ ] 3 | [ ] 4 | [ ] 5 | [ ] 6 | [ ] 7 | [ ] 8 | [ ] 9 | [ ] 10 |

none at
all

a great
deal

22. How much depression do you have?

[ ] 0 | [ ] 1 | [ ] 2 | [ ] 3 | [ ] 4 | [ ] 5 | [ ] 6 | [ ] 7 | [ ] 8 | [ ] 9 | [ ] 10

none at
all

a great
deal

To what extent are you <u>fearful</u> of:

23. Future diagnostic test

[ ] 0 | [ ] 1 | [ ] 2 | [ ] 3 | [ ] 4 | [ ] 5 | [ ] 6 | [ ] 7 | [ ] 8 | [ ] 9 | [ ] 10

no fear

extreme
fear

24. A second cancer

[ ] 0 | [ ] 1 | [ ] 2 | [ ] 3 | [ ] 4 | [ ] 5 | [ ] 6 | [ ] 7 | [ ] 8 | [ ] 9 | [ ] 10

no fear

extreme
fear

25. Recurrence of your cancer

[ ] 0 | [ ] 1 | [ ] 2 | [ ] 3 | [ ] 4 | [ ] 5 | [ ] 6 | [ ] 7 | [ ] 8 | [ ] 9 | [ ] 10

no fear

extreme
fear

26. Spreading (metastasis) of your cancer

[ ] 0 | [ ] 1 | [ ] 2 | [ ] 3 | [ ] 4 | [ ] 5 | [ ] 6 | [ ] 7 | [ ] 8 | [ ] 9 | [ ] 10

no fear

extreme
fear

Social Concerns

27. How distressing has your illness been for your family?

[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4	[ ] 5	[ ] 6	[ ] 7	[ ] 8	[ ] 9	[ ] 10

none at all   a great deal

28. Is the amount of support you receive from other s sufficient to meet your needs?

[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4	[ ] 5	[ ] 6	[ ] 7	[ ] 8	[ ] 9	[ ] 10

none at all   a great deal

29. To what degree has your illness or treatment interfered with your personal relationships?

[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4	[ ] 5	[ ] 6	[ ] 7	[ ] 8	[ ] 9	[ ] 10

none at all   a great deal

30. Is your sexuality impacted by your illness?

[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4	[ ] 5	[ ] 6	[ ] 7	[ ] 8	[ ] 9	[ ] 10

none at all   a great deal

31. To what degree has your illness or treatment interfered with your employment?

[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4	[ ] 5	[ ] 6	[ ] 7	[ ] 8	[ ] 9	[ ] 10

no problem   severe problem

32. To what degree has your illness or treatment interfered with your activities at home?

[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4	[ ] 5	[ ] 6	[ ] 7	[ ] 8	[ ] 9	[ ] 10

no   severe
problem   problem

33. How much isolation do you feel is caused by your illness or treatment?

| [ ] 0 | [ ] 1 | [ ] 2 | [ ] 3 | [ ] 4 | [ ] 5 | [ ] 6 | [ ] 7 | [ ] 8 | [ ] 9 | [ ] 10 |

none at   a great
all   deal

34. How much financial burden have you in curred as a result of your illness and treatment?

| [ ] 0 | [ ] 1 | [ ] 2 | [ ] 3 | [ ] 4 | [ ] 5 | [ ] 6 | [ ] 7 | [ ] 8 | [ ] 9 | [ ] 10 |

none at   a great
all   deal

Spiritual Well Being

35. How important to you is your participation in religious activities such as praying, going to church?

| [ ] 0 | [ ] 1 | [ ] 2 | [ ] 3 | [ ] 4 | [ ] 5 | [ ] 6 | [ ] 7 | [ ] 8 | [ ] 9 | [ ] 10 |

not at all   very
important   important

36. How important to you are other spiritual activities such as mediation?

| [ ] 0 | [ ] 1 | [ ] 2 | [ ] 3 | [ ] 4 | [ ] 5 | [ ] 6 | [ ] 7 | [ ] 8 | [ ] 9 | [ ] 10 |

not at all   very
important   important

37. How much has your spiritual life changed as a result of your cancer diagnosis?

| [ ] 0 | [ ] 1 | [ ] 2 | [ ] 3 | [ ] 4 | [ ] 5 | [ ] 6 | [ ] 7 | [ ] 8 | [ ] 9 | [ ] 10 |

less   more
important   important

38. How much uncertainty do you feel about your future?

[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4	[ ] 5	[ ] 6	[ ] 7	[ ] 8	[ ] 9	[ ] 10

not at all
uncertain   very
                                                                                            uncertain

39. To what extent has your illness made positive changes in your life ?

[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4	[ ] 5	[ ] 6	[ ] 7	[ ] 8	[ ] 9	[ ] 10

not at
all   a great
                                                                                            deal

40. Do you sense a purpose/missionfor your life or a reason for being alive?

[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4	[ ] 5	[ ] 6	[ ] 7	[ ] 8	[ ] 9	[ ] 10

none at
all   a great
                                                                                            deal

41. How hopeful do you feel?

[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4	[ ] 5	[ ] 6	[ ] 7	[ ] 8	[ ] 9	[ ] 10

not at all
hopeful   very
                                                                                            hopeful

Scoring

The scoring should be based on a scale of 0 = worst outcome to 10 = best outcome. Several items have reverse anchors and therefore when you code the items you will need to reverse the scores of those items. For example, if a participant circles "3" on such an item, (10-3 = 7), you would record a score of 7. The items to be reversed coded are: 1-7, 9, 16-27, 29-34 and 38. Subscale scores can be created for analysis purposes by adding all of the items within a subscale and creating a mean score.

Protocol source: https://www.phenxtoolkit.org/protocols/view/320902