



## 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.

Answer each question by marking the box to the left of your answer.

You are sometimes told to skip over some questions in this survey. When this happens, you will see an arrow with a note that tells you what questions to answer next, like this:

Yes

No - If No, go to #1 on page 3

### Contacting Your Cancer surgery Team

1. Cancer surgery team refers to the doctors, nurses, therapists, technicians, and their support staff involved with your cancer surgery through this cancer center. Since it was decided that you would have cancer surgery, did your cancer surgery team encourage you to contact them with questions between visits?

Yes, definitely

Yes, somewhat

No

2. Since it was decided that you would have cancer surgery, did your cancer surgery team tell you to call them immediately if you have certain symptoms or side effects?

Yes, definitely

Yes, somewhat

No

3. Since it was decided that you would have cancer surgery, did your cancer surgery team give you clear instructions about how to contact them after regular office hours?

Yes, definitely

Yes, somewhat

No

4. Since it was decided that you would have cancer surgery, did your cancer surgery team involve your family members or close friends in discussions about your cancer or cancer care as much as you wanted?

Yes, definitely

Yes, somewhat

No

5. When was the last time you received cancer surgery for cancer from this cancer center?

In the last 6 months

More than 6 months ago - If more than 6 months ago, end survey

### **Your Care Team from This Cancer Center**

6. In the last 6 months, how many times did you visit this cancer center to get care from your cancer surgery team? Do not include telephone calls or emails.

None - If None, end survey

1  to 5 times

6  to 10 times

11  or more times

7. In the last 6 months, did you contact this cancer center to get an appointment for an illness, injury, or condition that needed care right away?

Yes

No - If No, go to #9

8. In the last 6 months, when you contacted this cancer center to get an appointment for care you needed right away, how often did you get an appointment as soon as you needed?

Never

Sometimes

Usually

Always

9. In the last 6 months, did you make any appointments for a check - up or routine care at this cancer center?

Yes

No - If No, go to #11

10. In the last 6 months, when you made an appointment for a check - up or routine care at this cancer center, how often did you get an appointment as soon as you needed?

Never

Sometimes

Usually

Always

11. In the last 6 months, did you contact this cancer center with a medical question during regular office hours?

Yes

No - If No, go to #13

12. In the last 6 months, when you contacted this cancer center during regular office hours, how often did you get an answer to your medical question that same day?

Never

Sometimes

Usually

Always

### **Your Cancer Surgery Team**

13. Cancer surgery team refers to the doctors, nurses, therapists, technicians, and their support staff involved with your cancer surgery through this cancer center. In the last 6 months, how often did your cancer surgery team explain things in a way that was easy to understand?

Never

Sometimes

Usually

Always

14. In the last 6 months, how often did your cancer surgery team listen carefully to you?

Never

Sometimes

Usually

Always

15. In the last 6 months, how often did your cancer surgery team seem to know the important information about your medical history?

Never

Sometimes

Usually

Always

16. In the last 6 months, how often did your cancer surgery team show respect for what you had to say?

Never

Sometimes

Usually

Always

17. In the last 6 months, how often did your cancer surgery team spend enough time with you?

Never

Sometimes

Usually

Always

18. In the last 6 months, did your cancer surgery team order a blood test, x - ray,

or other test for you? Do not include cancer surgery.

Yes

No - If No, go to #20

19. In the last 6 months, when you had blood tests, x - rays, or other tests as part of your cancer treatment, how often did someone from this cancer center follow up to give you those results?

Never

Sometimes

Usually

Always

20. In the last 6 months, did you take any prescription medicine?

No - If No, go to #22

Yes

21. In the last 6 months, how often did you and your cancer surgery team talk about all the prescription medicines you were taking?

Never

Sometimes

Usually

Always

22. In the last 6 months, did you and your cancer surgery team talk about pain related to your cancer or cancer surgery?

Yes

No

23. In the last 6 months, were you bothered by pain from your cancer or cancer surgery?

Yes

No - If No, go to #25

24. In the last 6 months, did your cancer surgery team advise you about or help you deal with this pain?

Yes, definitely

Yes, somewhat

No

25. In the last 6 months, did you and your cancer surgery team talk about any changes in your energy levels related to your cancer or cancer surgery?

Yes

No

26. In the last 6 months, were you bothered by changes in your energy levels related to your cancer or cancer surgery?

Yes

No - If No, go to #28

27. In the last 6 months, did your cancer surgery team advise you about or help you deal with these changes in your energy levels?

Yes, definitely

Yes, somewhat

No

28. In the last 6 months, did you and your cancer surgery team talk about any emotional problems, such as anxiety or depression, related to your cancer or cancer surgery?

Yes

No

29. In the last 6 months, were you bothered by any emotional problems, such as anxiety or depression, related to your cancer or cancer surgery?

Yes

No - If No, go to #31

30. In the last 6 months, did your cancer surgery team advise you about or help you deal with these emotional problems?

Yes, definitely

Yes, somewhat

No

31. Additional services to manage your cancer care at home include home health care, special medical equipment, or special supplies. In the last 6 months, did you and your cancer surgery team talk about these additional services?

Yes

No

32. In the last 6 months, did you and your cancer surgery team talk about things you can do to maintain your health during cancer treatment such as what to eat and what exercises to do?

Yes, definitely

Yes, somewhat

No

33. Using any number from 0 to 10, where 0 is the worst cancer surgery team possible and 10 is the best cancer surgery team possible, what number would you use to rate your cancer surgery team?

0  Worst cancer surgery team possible

1

2

3

4

5

6

7

8

9

10  Best cancer surgery team possible

34. An interpreter is someone who helps you talk with others who do not speak your language. Interpreters can include staff from this cancer center, telephone interpreters, friends, or family members. In the last 6 months, was there any time when you needed an interpreter at this cancer center?

Yes

No - If No, go to #36

35. In the last 6 months, when you needed an interpreter to speak with your cancer surgery team, how often did you get one?

Never

Sometimes

Usually

Always

36. Considering all your cancer care at this cancer center, using any number from 0 to 10, where 0 is the worst overall cancer care experience possible and 10 is the best overall cancer care experience possible, what number would you use to rate your overall cancer care experience?

0  Worst overall cancer care experience possible

1

2

3

4

5

6

7

8

9

10  Best overall cancer care experience possible

### **Access**

37. In the last 6 months, did you contact this cancer center with a medical question after regular office hours?

Yes

No - If No, go to #39



38. In the last 6 months, when you contacted this cancer center after regular office hours, how often did you get an answer to your medical questions as soon as you needed?

Never

Sometimes

Usually

Always

39. Wait time includes time spent in the waiting room and exam room. In the last 6 months, how often did you see the person you came to see within 15 minutes of your appointment time?

Never

Sometimes

Usually

Always

#### **Information from Providers**

40. Since it was decided that you would have cancer surgery, did your cancer surgery team clearly explain how your cancer and cancer surgery] could affect your normal daily activities?

Yes, definitely

Yes, somewhat

No

41. In the last 6 months, did your cancer surgery team tell you what the next steps in your cancer surgery would be?

Yes, definitely

Yes, somewhat

No

42. In the last 6 months, how often did your cancer surgery team explain those results in a way that was easy to understand?

Never

Sometimes

Usually

Always

43. In the last 6 months, did your cancer surgery team prescribe medicine that you had not taken before?

Yes

No

44. In the last 6 months, did your cancer surgery team explain what that medicine was for in a way that was easy to understand?

Yes, definitely

Yes, somewhat

No

### **Shared Decision Making**

45. Since your cancer was diagnosed, did a doctor or other health care professional at this cancer center talk with you about more than one way to treat your cancer?

Yes

No - If No, go to #49

46. Since your cancer was diagnosed, did a doctor or other health care professional at this cancer center clearly explain the advantages of each choice for cancer treatment, including the treatments you did not get?

Yes, definitely

Yes, somewhat

No

47. Since your cancer was diagnosed did a doctor or health care professional at this cancer center clearly explain the disadvantages of each choice for cancer treatment, including the treatments you did not get?

Yes, definitely

Yes, somewhat

No

48. Since your cancer was diagnosed, did a doctor or other health care professional at this cancer center ask for your opinion about each choice of cancer treatment, including the treatments you did not get?

Yes, definitely

Yes, somewhat

No

49. Since your cancer was diagnosed, did a doctor or other health care professional at this cancer center talk with you about the reason you might want to have cancer surgery?

Yes, definitely

Yes, somewhat

No

50. Since your cancer was diagnosed, did a doctor or other health care professional at this cancer center talk with you about the reasons you might not want to have cancer surgery?

Yes, definitely

Yes, somewhat

No

51. Since your cancer was diagnosed, when you talked about having cancer surgery, did a doctor or other health care professional at this cancer center ask you what you thought was best for you?

Yes, definitely

Yes, somewhat

No

52. Since your cancer was diagnosed, did a doctor or health professional at this cancer center involve you in decisions about your cancer treatment as much as you wanted?

Yes, definitely

Yes, somewhat

No

Protocol source: <https://www.phenxtoolkit.org/protocols/view/320801>