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 would like to know what unmet needs you have had IN THE LAST MONTH as a result of having cancer now or in the past. An unmet need is a need that you have not been able to satisfy.

For each question, place an X next to the number that best describes your level of unmet need IN THE LAST MONTH. Please answer each question, even if you feel there is no way to solve the problem or you do not have any unmet needs.

0	No unmet need – This was not a problem for me as a result of having cancer now or in the past.
1	Low unmet need – I needed a small amount of help with this problem but was not able to get it.
2	Moderate unmet need – I needed a moderate amount of help with this problem but was not able to get it.
3	High unmet need – I needed a high amount of help with this problem but was not able to get it.
4	Very high unmet need – I needed a very high amount of help with this problem but was not able to get it.

We know that your unmet needs may change over time. In this survey, we want to

know only about the unmet needs you have had IN THE LAST MONTH.

Please go to the next page to begin the survey.

A. Unmet Information Needs: This part of the survey is about unmet needs that relate to finding information IN THE LAST MONTH.

	No Unmet Need	Low Unmet Need	Moderate Unmet Need	High Unmet Need	Very High Unmet Need
For each statement, place an X after the choice that best describes your level of unmet.					
1. Finding information about complementary or alternative therapies	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4
2. Dealing with fears about cancer spreading	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4
3. Dealing with worry about whether the treatment has worked	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4

B. Unmet Work and Financial Needs: This part of the survey is about unmet needs you may have had about your job and finances IN THE LAST MONTH.

	No Unmet Need	Low Unmet Need	Moderate Unmet Need	High Unmet Need	Very High Unmet Need
For each statement, place an X next to the choice that best describes your level of unmet.					

4. Worry about earning money	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4
5. Having to take a pensions or disability allowance	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4
6. Paying household bills or other payments	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4
7. Finding what type of financial assistance is available and how to obtain it	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4
8. Finding car parking that I can afford at the hospital or clinic	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4
9. Understanding what is covered by my medical insurance or benefits	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4
10. Knowing how much time I would need away from work	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4
11. Doing work around the house (cooking, cleaning, home repairs, etc.)	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4

C. Unmet Needs for ACCESS and Continuity of Care: This part of the survey is about unmet needs that relate to medical care IN THE LAST MONTH.

	No Unmet Need	Low Unmet Need	Moderate Unmet Need	High Unmet Need	Very High Unmet Need
For each statement, place and X next to the choice that best describes your level of unmet need.					

12. Having access to cancer services close to my home	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4
13. Getting appointments with specialists quickly enough (oncologist, surgeon, etc.)	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4
14. Getting test results quickly enough	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4
15. Having access to care from other health specialists (dieticians, physiotherapists, occupational therapists)	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4
16. Making sure I had enough time to ask my doctor or nurse questions	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4
17. Getting the health care team to attend promptly to my physical needs	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4

D. Unmet Coping, Sharing and Emotional Needs: This part of the survey is about unmet needs that relate to your relationships with others and your emotional health IN THE LAST MONTH.

	No Unmet Need	Low Unmet Need	Moderate Unmet Need	High Unmet Need	Very High Unmet Need
For each statement, place an X next to the choice that best describes your level of unmet need.					
18. Telling others how I was feeling emotionally	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4

19. Finding someone to talk to who understands and has been through a similar experience	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4
20. Dealing with people who expect me to be "back to normal"	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4
21. Dealing with people accepting that having cancer has changed me as a person	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4
22. Dealing with reduced support from others when treatment has ended	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4
23. Dealing with feeling depressed	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4
24. Dealing with feeling tired	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4
25. Dealing with feeling stressed	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4
26. Dealing with feeling lonely	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4
27. Dealing with not being able to feel 'normal'	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4
28. Trying to stay positive	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4
29. Coping with having a bad memory or lack of focus	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4

30. Dealing with changes in how my body appears	[ ] 0	[ ] 1	[ ] 2	[ ] 3	[ ] 4

Protocol source: https://www.phenxtoolkit.org/protocols/view/321201