

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.

Please answer the following questions by placing a tick in any of the boxes for each of the question.

	Not at all	A little	Sometimes	A lot	All the time
Q1: I am afraid that my cancer may recur	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Q2: I am worried or anxious about the possibility of cancer recurrence	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
Q3: How often have you worried about the possibility of getting cancer again	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

Q4: I get waves of strong feelings about the cancer coming back											
	[] 1	[] 2	[] 3	[] 4	[] 5						
Q5: I think about the cancer returning when I didn't mean to											
	[] 1	[] 2	[] 3	[] 4	[] 5						
Q6: I examine myself to see if I have physical signs of cancer											
	[] 1	[] 2	[] 3	[] 4	[] 5						
	Not at all										A great deal
Q7: To what extent does worry about getting cancer again spill over											
	[] 0	[] 1	[] 2	[] 3	[] 4	[] 5	[] 6	[] 7	[] 8	[] 9	[] 10

or intrude on your thoughts and activities											
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† FCR4 is sum of first 4 items (Q1 to Q4)

Scoring

The scoring system is ‘1 = not at all’, ‘2 = a little’, ‘3 = sometimes’, ‘4 = a lot’, and ‘5 = all the time’. The 7th item is used to assess the extent to which FCR interferes with the patient’s thoughts and activities and is scored on a 11-point scale, with a ‘0’ indicating ‘not at all’ and ‘10’ indicating ‘a great deal’. For each individual item, a score ≥ 4 on questions 1 to 6 (ranging from 1 to 5), or ≥ 7 on question 7 (ranging from 0 to 10) indicates a significant level (severity) of fear of cancer recurrence⁶.

Although no definite clinically meaningful cut point is available to decide patients’ FCR, the single item or total (sum) scores can be used for screening and to identify patients’ severity of FCR. The total score is ranged from 6 to 40, with higher the score indicating higher level of FCR.

Protocol source: <https://www.phenxtoolkit.org/protocols/view/320401>