



## 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.

Thank you for taking the time to fill out this survey.

This survey asks about your experiences with doctors and other health

professionals such as nurses and physician assistants. This is not a test, and there are no right and wrong answers.

### Instructions:

- Please share your honest opinions. All of your answers will be kept private. The information will not be reported back to your doctors, nurses, or anyone else who provides care.
- Please use a **BLACK** or **DARK BLUE** ink pen to mark your answers.
- Be sure to read all of the answer choices before marking your answer.

### Sharing Information

1. How often do your doctors and other health professionals...

a. Talk with you about your concerns and questions?

Never

Rarely

Sometimes

Often

Always

b. Give you helpful information, even when you don't ask for it?

Never

Rarely

Sometimes

Often

Always

c. Make sure you have the information you need?

Never

Rarely

Sometimes

Often

Always

d. Help you understand the information you need to know?

Never

Rarely

Sometimes

Often

Always

e. Make sure your questions are answered?

Never

Rarely

Sometimes

Often

Always

2. How much do your doctors and other health professionals make you feel comfortable asking questions? \*

Not at all

Not very much

Somewhat

A lot

A great deal

### **Relationships with Doctors and Other Health Professionals**

3. How much can you depend on your doctors and other health professionals to give you the care you need?

Not at all

Not very much

Somewhat

A lot

A great deal

4. How often do your doctors and other health professionals...

a. Show they care about you?

Never

Rarely

Sometimes

Often

Always

b. Remember details about you between visits?

Never

Rarely

Sometimes

Often

Always

c. Have open and honest communication with you? \*

Never

Rarely

Sometimes

Often

Always

d. Listen carefully to what you have to say?

Never

Rarely

Sometimes

Often

Always

5. How much do your doctors and other health professionals seem well informed about your type of cancer?

Not at all

Not very much

Somewhat

A lot

A great deal

6. Different doctors and health professionals are often involved in a patient's care. How well do your doctors and other health professionals explain what they each do?

Poorly

Not very well

Fairly well

Very well

Outstanding

### **Making Decisions**

Many decisions need to be made in cancer care, such as decisions about treatment choices, where to go for care, or how to manage side effects.

Please think about all of the decisions there have been in your care.

7. How often do your doctors and other health professionals involve you in making decisions about your care?

- Never
- Rarely
- Sometimes
- Often
- Always
- Does not apply/there have not been any decisions

8. How well do your doctors and other health professionals ...

a. Explain the different choices you have?

- Poorly
- Not Very Well
- Fairly Well
- Outstanding
- Does Not Apply

b. Explain what they recommended?

- Poorly
- Not Very Well
- Fairly Well
- Outstanding
- Does Not Apply

9. How much do your doctors and other health professionals...

a. Show interest in what you say about the decisions?

- Not at all
- Not Very Much
- Somewhat
- A Lot
- A Great Deal

Does Not Apply

b. Give you information and resources to help you make decisions? \*

Not at All

Not Very Much

Somewhat

A Lot

A Great Deal

Does Not Apply

### **Attention to Your Emotions**

10. How often do your doctors and other health professionals give the attention you need to your feelings and emotions?

Never

Rarely

Sometimes

Often

Always

Does not apply/I do not want attention to my feelings and emotions

11. How much do your doctors and other health professionals...

a. Pay attention to how you are doing emotionally?

Not at All

Not Very Much

Somewhat

A Lot

A Great Deal

Does Not Apply

b. Show concern for your feelings, not just your illness?

- Not at All
- Not Very Much
- Somewhat
- A Lot
- A Great Deal
- Does Not Apply

c. Show concern for how your family is doing emotionally?

- Not at All
- Not Very Much
- Somewhat
- A Lot
- A Great Deal
- Does Not Apply

d. Make you feel comfortable to talk about your fears, stress, and other feelings?

- Not at All
- Not Very Much
- Somewhat
- A Lot
- A Great Deal
- Does Not Apply

12. How well do your doctors and other health professionals talk with you about how to cope with any fears, stress, and other feelings? \*

- Poorly
- Not very well
- Fairly well
- Very well

Outstanding

Does not apply

### **Taking Care of Yourself**

13. How well do your doctors and other health professionals help you understand ways you can take care of your health?

Poorly

Not very well

Fairly well

Very well

Outstanding

14. How much do your doctors and other health professionals talk with you about...

a. How cancer is affecting your everyday life?

Not at All

Not Very Much

Somewhat

A Lot

A Great Deal

Does Not Apply

b. Ways you can manage any side effects or symptoms?

Not at All

Not Very Much

Somewhat

A Lot

A Great Deal

Does Not Apply



c. How your family can help care for you?

- Not at All
- Not Very Much
- Somewhat
- A Lot
- A Great Deal
- Does Not Apply

d. Any concerns you have about taking care of yourself?

- Not at All
- Not Very Much
- Somewhat
- A Lot
- A Great Deal
- Does Not Apply

15. How often do your doctors and other health professionals make sure you understand the steps in your care? \*

- Never
- Rarely
- Sometimes
- Often
- Always

### **Dealing with Uncertainty**

16. Cancer patients often face uncertainties about their cancer. For example, patients may not know what will happen, how treatment is working, and how to make sense of different information and opinions. How well do your doctors and other health professionals help you deal

with the uncertainties about your cancer? \*

Poorly

Not very well

Fairly well

Very well

Outstanding

Does not apply/have not been any uncertainties

17. How much do your doctors and other health professionals help you understand ...

a. If you are getting better or worse?

Not at All

Not Very Much

Somewhat

A Lot

A Great Deal

Does Not Apply

b. The goal of your care?

Not at All

Not Very Much

Somewhat

A Lot

A Great Deal

Does Not Apply

c. What is likely to happen with your cancer?

Not at All

Not Very Much

- Somewhat
- A Lot
- A Great Deal
- Does Not Apply

d. How your symptoms may change?

- Not at All
- Not Very Much
- Somewhat
- A Lot
- A Great Deal
- Does Not Apply

18. Patients often get information from different places. How well do your doctors and other health professionals help you understand what information is most important?

- Poorly
- Not very well
- Fairly well
- Very well
- Outstanding
- Does not apply/I have not gotten information from different places

### Scoring

Each item included in the PCC-Ca© instrument consists of a question stem and five response options. The response options are scored from 1 to 5, with higher scores representing better communication; for example, where 1 = Never and 5 = Always. There are no reverse scored items. Some items have a sixth does not apply” option. This response is not scored. The PCC-Ca-36© measure provides scores for each of the six PCC core functions and overall PCC. The PCCCa-6© measure provides a single score for overall PCC only. On the PCC-Ca-36 measure, scores for each PCC function are an average of the item responses within each function. Scores across the entire PCC-Ca-36© measure for the overall PCC score are an

average of all of the items. Scores are averaged, not summed, across items and functions so that missing data do not result in an artificially low score. Table 1 presents scoring instructions for both measures.

Function	Scoring for PCC-Ca-36©	Scoring for PCC-Ca-6©
Exchanging Information	Mean of “Sharing Information” item responses (1a, 1b, 1c, 1d, 1e, and 2)	
Fostering Healing Relationships	Mean of “Relationships with Doctors and Other Health Professionals” item responses (3, 4a, 4b, 4c, 4d, 5, and 6)	
Making Decisions	Mean of “Making Decisions” item responses (7, 8a, 8b, 9a, and 9b)	
Responding to Emotions	Mean of “Attention to Your Emotions” item responses (10, 11a, 11b, 11c, 11d, and 12)	
Enabling Patient Self-Management	Mean of “Taking Care of Yourself” item responses (13, 14a, 14b, 14c, 14d, and 15)	
Managing Uncertainty	Mean of “Dealing with Uncertainty” item responses (16, 17a, 17b, 17c, 17d, and 18)	
Overall PCC	Mean of all 36 item responses	Mean of all 6 item responses with an asterisk (*)

Protocol source: <https://www.phenxtoolkit.org/protocols/view/320701>