

Appendix E. PCORI Patient Interview 2 Questionnaire

Interview #2 occurs Day 1 of 2nd Chemo Cycle (± 3 Day 1/Day 1 preferred)
 Date of Day 1 of 2nd Chemo Cycle: _____
 Name of Person Entering Data: _____

PCORI Patient #: _____
 Date of Interview #2: _____
 Name of Interviewer: _____








Patient-Defined Treatment Success & Preferences in Stage IV Lung Cancer Patients

A. Tolerance of Side Effects

Interview #2

1. Current cancer treatment may have unwanted side effects; sometimes mild, sometimes more severe. Each person is different. Research shows that people with lung cancer who receive chemotherapy may experience one or more unwanted side effects.

For each of the following possible side effects, pick the face from the Distress Rating Scale (see supplied card: "Distress Rating Scale") that represents your level of tolerance, if you were to experience it. (Circle one number per row. If you know of other possible adverse side effects that may be associated with chemotherapy, list those in "other" and rate your tolerance level using Faces 1-7.) Sample short instructions: "What distress face # would you give for each of the side effects, if you were to experience it (that side effect), how distressed do you think you would be?"

Possible Side Effects							
a. loss of appetite / weight loss	1	2	3	4	5	6	7
b. brittle nails	1	2	3	4	5	6	7
c. cough	1	2	3	4	5	6	7
d. decreased energy level	1	2	3	4	5	6	7
e. diarrhea	1	2	3	4	5	6	7
f. difficulty sleeping	1	2	3	4	5	6	7
g. dizziness	1	2	3	4	5	6	7
h. dry, peeling skin	1	2	3	4	5	6	7
i. fatigue	1	2	3	4	5	6	7
j. hair loss	1	2	3	4	5	6	7
k. increased chance of bleeding	1	2	3	4	5	6	7
l. itchy skin	1	2	3	4	5	6	7
m. jaundice (yellow skin)	1	2	3	4	5	6	7
n. more trips to clinic for chemo	1	2	3	4	5	6	7
o. nausea (sick to stomach)	1	2	3	4	5	6	7
p. numbness and / or tingling	1	2	3	4	5	6	7
q. pain	1	2	3	4	5	6	7
r. shortness of breath	1	2	3	4	5	6	7
s. other: _____	1	2	3	4	5	6	7

2. Which of the above unwanted side effects of treatment would you hate the most? (Enter a single letter from "a" to "s" above.): _____

3. To reach an important personal goal, how long would you be willing to tolerate a higher chance of irritating or uncomfortable side effects of chemotherapy? (Circle one.)
 a. no time period b. months c. years

4. Would you be willing to tolerate ALL of the side effects of treatment listed in question 1 above if it meant you might live longer? (Mark one.)
 Yes No Don't Know

5. How would you define "treatment success" (of your chemotherapy)? (Write in response.):

B. Quality of Life

6. Below is a list of statements that other people with your illness have said are important. (Circle one number per row to indicate your response as it applies to the past 7 days.)

A. Physical well-being <i>In the past 7 days. . . .</i>	Not at all	A little bit	Some-what	Quite a bit	Very much
a. I have a lack of energy.....	0	1	2	3	4
b. I have nausea.	0	1	2	3	4
c. Because of my physical condition, I have trouble meeting the needs of my family ...	0	1	2	3	4
d. I have pain	0	1	2	3	4
e. I am bothered by side effects of treatment	0	1	2	3	4
f. I feel ill	0	1	2	3	4
g. I am forced to spend time in bed	0	1	2	3	4
B. Functional well-being <i>In the past 7 days. . . .</i>	Not at all	A little bit	Some-what	Quite a bit	Very much
a. I am able to work (include work at home) .	0	1	2	3	4
b. My work (include work at home) is fulfilling.	0	1	2	3	4
c. I am able to enjoy life	0	1	2	3	4
d. I have accepted my illness.....	0	1	2	3	4
e. I am sleeping well	0	1	2	3	4
f. I am enjoying the things I usually do for fun	0	1	2	3	4
g. I am content with the quality of my life right now	0	1	2	3	4
C. Additional concerns <i>In the past 7 days. . . .</i>	Not at all	A little bit	Some-what	Quite a bit	Very much
a. I have been short of breath	0	1	2	3	4
b. I am losing weight	0	1	2	3	4
c. My thinking is clear	0	1	2	3	4
d. I have been coughing	0	1	2	3	4
e. I have a good appetite	0	1	2	3	4
f. I feel tightness in my chest	0	1	2	3	4
g. Breathing is easy for me	0	1	2	3	4

C. Ranking Exercise

7. Instructions: Below are some unwanted side effects of chemotherapy that most people would prefer not to be bothered with; however, no one knows ahead of time how any particular individual will respond to chemotherapy medications.

The object of this exercise is to sort the possible unwanted side effects from “bad” (1st) to “least bad” (9th); that is, to order the cards from the one you would hate the most (on top) to the one you would hate the least (on the bottom).

- To Begin:**
- ① Place the three heading cards (red ink), conveniently before you from Hate–Most (on left), Hate–Medium (in the middle), and Hate–Least (on right).
 - ② Next, sort the remaining cards into 3 stacks of 3 each under each heading: “Hate–Most,” “Hate–Medium,” to “Hate–Least.”
 - ③ Last, order each of the 3 cards within a group with the one you hate most on top (1st) and the next most dreaded side effect 2nd and the third most dreaded side effect 3rd in each of the 3 columns. You should end up with the 9 cards in order from Hate–Most (the side effect you would dread most) on the top of the final stack or column to Hate–Least (the side effect that is the “least bad” for you) on the bottom of the final stack or column.

Note: Interviewer may demonstrate how to complete the exercise or assist in placing the cards in order according to the participant’s wishes / directions. At the conclusion of the exercise, interviewer records the numbers from 1 to 9 (most hated to least hated) next to the side effect in the following list.

Possible Side Effects	Rank Order 1 to 9 Bad...Least Bad
A. brittle nails	A =
B. decreased energy (excessive fatigue)	B =
C. dizziness	C =
D. unusual / increased bleeding	D =
E. jaundice (yellow skin)	E =
F. more trips to clinic for treatment	F =
G. numbness and / or tingling	G =
H. shortness of breath	H =
I. a lot more expensive	I =

Continued on next page










D. Side Effects Experienced

8. Since your first chemotherapy treatment, what has your personal experience been with the side effects listed below?

For each side effect in Column 1 indicate if you experienced it at all. (For each possible side effect listed, first work down Column 1, mark Yes/No in Column 2. Use "other" for adverse side effects that you experienced that are not listed.)

For all "Yes" answers ONLY: indicate which face most closely represents how bad that side effect was, or is, for you (see card that shows numbered faces). (Circle one number that corresponds to the appropriate face in Column 3 for "Yes" answers only. Face 1 = no distress at all....Face 7 = worst possible distress.)

Column 1 Possible Side Effects	Column 2 Did you experience it?	Column 3 How bad was it for you?						
								
a. loss of appetite / weight loss	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
b. brittle nails	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
c. cough	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
d. decreased energy level	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
e. diarrhea	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
f. difficulty sleeping	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
g. dizziness	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
h. dry, peeling skin	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
i. fatigue	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
j. hair loss	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
k. unusual / increased bleeding	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
l. itchy skin	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
m. jaundice (yellow skin)	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
n. nausea (sick to stomach)	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
o. numbness and / or tingling	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
p. pain	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
q. shortness of breath	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
r. other: _____	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7

9. Of the side effects that you experienced above (your "Yes" answers), which one was your worst side effect? (Enter a single letter, choose from "a" to "r" in above list): _____

10. For the side effect that you experienced that was the worst one (named in #9 above), describe what it was like for you. (short answer, write-in)

11. For the side effect that you experienced that was the worst one (named in #8 above), describe how long it lasted for you. (short answer, write-in)

12. Other comments? (write-in)

THANK YOU VERY MUCH!

We sincerely appreciate your participation.

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