

Appendix E. Outcome Instruments

TALKING ABOUT HEALTH CARE

This first group of questions is about discussions you may have recently had with the doctor who is in this study with you. Your doctor, in some cases, may be a nurse practitioner.

During your appointment on _____ with _____:

1. Did you discuss with this doctor the kind of medical care you would want if you were too sick to speak for yourself? *(Please check 1 box)*

- 1 Yes
0 No
9 I don't know

2. If "NO" or "I DON'T KNOW": Would you like to have had a discussion of this type with this doctor? *(Please check 1 box)*

- 1 Yes
0 No
9 I don't know

3. If "YES": To what extent did the discussion meet your needs for information about your medical care? *(Please check 1 box)*

Not at all											Completely
0	1	2	3	4	5	6	7	8	9	10	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

4. Would you like to have additional discussions with this doctor about this? *(Please check 1 box)*

- 1 Yes
0 No
9 I don't know

CHOOSING CARE

We are also interested in the kind of care you might choose at this time. We asked you similar questions when you joined the study, but because people's choices sometimes change, we are asking these questions again.

1. If you had to make a choice at this time, would you prefer a plan of medical care that focuses on extending life as much as possible, even if it means having more pain and discomfort, or would you want a plan of medical care that focuses on relieving pain and discomfort as much as possible, even if that means not living as long? (Please check 1 box)

- 0 Extending life, even if it means having more pain and discomfort
- 1 Relieving pain and discomfort as much as possible, even if that means not living as long
- 9 I'm not sure which I would choose

2. Using those same categories, which of the following best describes the focus of the medical care you are currently receiving? (Please check 1 box)

- 0 Extending life, even if it means having more pain and discomfort
- 1 Relieving pain and discomfort as much as possible, even if that means not living as long
- 9 I don't know, not sure

QUALITY OF COMMUNICATION

The following questions are about how well _____ talks with you about your care. We know that many people think very highly of their doctors. To help us improve communication between doctors and patients, please be critical.

Please rate _____ on each of the following questions using a scale from 0 (“The very worst I could imagine”) to 10 (“The very best I could imagine”). If you cannot rate your doctor on a question because he or she has not done it, please check the box for “My doctor has not done this.” You may also check the box for “I do not know.”

How good is your doctor at: *(Please check 1 box for each item)*

1. Talking with you about your feelings concerning the possibility that you might get sicker?

The very worst I could imagine											The very best I could	<i>My doctor has not done this</i>	<i>I do not know</i>
	0	1	2	3	4	5	6	7	8	9	10	888	999
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. Talking with you about the details concerning the possibility that you might get sicker?

The very worst I could imagine											The very best I could	<i>My doctor has not done this</i>	<i>I do not know</i>
	0	1	2	3	4	5	6	7	8	9	10	888	999
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3. Talking to you about how long you might have to live?

The very worst I could imagine											The very best I could	<i>My doctor has not done this</i>	<i>I do not know</i>
	0	1	2	3	4	5	6	7	8	9	10	888	999
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. Talking with you about what dying might be like?

The very worst I could imagine										The very best I could		My doctor has not done this	I do not know
0	1	2	3	4	5	6	7	8	9	10			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	888	999
												<input type="checkbox"/>	<input type="checkbox"/>

5. Involving you in the decisions about the treatments that you want if you get too sick to speak for yourself?

The very worst I could imagine										The very best I could		My doctor has not done this	I do not know
0	1	2	3	4	5	6	7	8	9	10			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	888	999
												<input type="checkbox"/>	<input type="checkbox"/>

6. Asking about the things in life that are important to you?

The very worst I could imagine										The very best I could		My doctor has not done this	I do not know
0	1	2	3	4	5	6	7	8	9	10			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	888	999
												<input type="checkbox"/>	<input type="checkbox"/>

7. Asking about your spiritual or religious beliefs?

The very worst I could imagine										The very best I could		My doctor has not done this	I do not know
0	1	2	3	4	5	6	7	8	9	10			
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	888	999
												<input type="checkbox"/>	<input type="checkbox"/>

YOUR FEELINGS

These questions are about feelings you may have experienced **over the past 2 weeks**. We are interested in your feelings because having a serious illness may affect how you feel emotionally as well as physically. Please check the box that best describes how often, over the **past 2 weeks**, you have been bothered by any of the following problems. Answers range from “Not at all” to “Nearly every day.” Please check **1** box for each problem. You may skip any question that you do not want to answer.

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
2. Feeling down, depressed, or hopeless	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
3. Trouble falling asleep, staying asleep, or sleeping too much	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
4. Feeling tired or having little energy	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
5. Poor appetite or overeating	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
6. Feeling bad about yourself or that you are a failure or have let yourself or your family down	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
7. Trouble concentrating on things, such as reading the newspaper or watching television	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
8. Moving or speaking so slowly that other people could have noticed, or the opposite—being so fidgety or restless that you have been moving around a lot more than usual	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people? *(Please check 1 box)*

Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

YOUR FEELINGS—A FEW MORE QUESTIONS

Over the **past 2 weeks**, how often have you been bothered by any of the following problems? Answers range from “Not at all” to “Nearly every day.” Please check 1 box for each problem.

	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious, or on edge	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
2. Not being able to stop or control worrying	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
3. Worrying too much about different things	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
4. Trouble relaxing	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
5. Being so restless that it is hard to sit still	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
6. Becoming easily annoyed or irritated	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
7. Feeling afraid, as if something awful might happen	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people? *(Please check 1 box)*

Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>