

**NEST13 Interview Script**  
Patient

**Interviewer:** Today I would like to ask you about how you are, using scripted questions. Initially, we'll begin with a series of 13 questions. The questions are really brief. At the end of each question, I will give you a scale of zero to 10. In the first group of questions, zero indicates "none," "not at all" or "never." Ten is "a great deal," "completely" or "constantly." Please give the number that best describes how you are feeling. After I ask each question, I will state what these numbers mean again.

1. How much of a financial hardship is your illness for you or your family?

None	1	2	3	4	5	6	7	8	9	A great deal
0			3							10

Proceed w/more questions?	
<input type="checkbox"/> Yes	<input type="checkbox"/> No
NEST48, 1	N/A

2. How much trouble do you have getting the medical care you need?

None	1	2	3	4	5	6	7	8	9	A great deal
0			3							10

Proceed w/more questions?	
<input type="checkbox"/> Yes	<input type="checkbox"/> No
NEST48, 2	N/A

3. How much help do you need with things like getting meals or getting to the doctor?

None	1	2	3	4	5	6	7	8	9	A great deal
0			3							10

Proceed w/more questions?	
<input type="checkbox"/> Yes	<input type="checkbox"/> No
NEST48, 3	N/A

**NEST13 Interview Script**  
Patient

4. How much does this illness seem senseless and meaningless?

Not at all	A great deal (completely)									
0	1	2	3	4	5	6	7	8	9	10
						6				

Proceed w/more questions?	
<input type="checkbox"/> Yes	<input type="checkbox"/> No
NEST48, 4	N/A

5. How much do you suffer from physical symptoms such as pain, shortness of breath, fatigue, bowel or urination problems?

Not at all	A great deal									
0	1	2	3	4	5	6	7	8	9	10
			3							

Proceed w/more questions?	
<input type="checkbox"/> Yes	<input type="checkbox"/> No
ESAS	N/A

6. How often do you feel confused or anxious or depressed?

Never	Constantly (always)									
0	1	2	3	4	5	6	7	8	9	10
			3							

Proceed w/more questions?	
<input type="checkbox"/> Yes	<input type="checkbox"/> No
ESAS	N/A

**Interviewer:** In the second group of questions, zero indicates “anytime I want,” “a great deal” or “completely.” Ten for these questions is “never” or “not at all.” So, the scale is almost the opposite of the questions that you just answered. Please give the number that best describes how you are feeling. After I ask each question, I will state what these numbers mean again.

7. How often is there someone to confide in?

Anytime I want	Never									
0	1	2	3	4	5	6	7	8	9	10
						6				

Proceed w/more questions?	
<input type="checkbox"/> Yes	<input type="checkbox"/> No
NEST48, 7	N/A

**NEST13 Interview Script**  
Patient

8. How much does religious belief or your spiritual life contribute to your sense of purpose?

A great deal (completely)										Not at all											
0	1	2	3	4	5	6	7	8	9	10	0	1	2	3	4	5	6	7	8	9	10

<b>Proceed w/more questions?</b>	
<input type="checkbox"/> Yes	<input type="checkbox"/> No
NEST48, 8	N/A

9. How much have you settled your relationships with the people close to you?

Completely										Not at all											
0	1	2	3	4	5	6	7	8	9	10	0	1	2	3	4	5	6	7	8	9	10

<b>Proceed w/more questions?</b>	
<input type="checkbox"/> Yes	<input type="checkbox"/> No
NEST48, 9	N/A

10. Since your illness, how much do you live life with a special sense of purpose?

Completely										Not at all											
0	1	2	3	4	5	6	7	8	9	10	0	1	2	3	4	5	6	7	8	9	10

<b>Proceed w/more questions?</b>	
<input type="checkbox"/> Yes	<input type="checkbox"/> No
NEST48, 10	N/A

11. How much do you feel your doctors and nurses respect you as an individual?

Completely										Not at all											
0	1	2	3	4	5	6	7	8	9	10	0	1	2	3	4	5	6	7	8	9	10

<b>Proceed w/more questions?</b>	
<input type="checkbox"/> Yes	<input type="checkbox"/> No
NEST48, 11	N/A

**NEST13 Interview Script**  
Patient

12. How clear is the information from the medical team about what to expect regarding your illness?

Completely										Not at all
0	1	2	3	4	5	6	7	8	9	10

Proceed w/more questions?	
<input type="checkbox"/> Yes	<input type="checkbox"/> No
NEST48, 12	N/A

13. How much do you feel that the medical care you are getting fits with your goals?

Completely										Not at all
0	1	2	3	4	5	6	7	8	9	10

Intervene?	
<input type="checkbox"/> Yes	<input type="checkbox"/> No

**IF THERE ARE NO SCORES WHERE THE CUT OFF HAS BEEN EXCEEDED, CLOSE THE INTERVIEW.**

**IF THERE ARE SCORES WHERE THE CUT OFF WAS EXCEEDED, PROCEED TO NEST48 AND/OR ESAS.**

**NEST48 Interview Script**  
Patient

**NOTE: THE NEST48 INTERVIEW OCCURS AFTER NEST13 AND ONLY IF THE PATIENT'S SCORE WAS GREATER THAN THE CUT-OFF SCORE FOR NEST13 ITEMS 1 THROUGH 4 AND 7 THROUGH 12.**

**Interviewer:** Like before, the questions are really brief. At the end of each question, I will give you a scale of zero to 10 and ask for a number that best aligns with your perspective. Zero indicates “none of the time,” and 10 indicates “all of the time.”

Item	Question for patient	0 = None of the time	1	2	3	4	5	6	7	8	9	10 = All of the time	Intervene?
<b>NEST13, ITEM 1:</b> ASK THE FOLLOWING QUESTION IF PATIENT'S SCORE EXCEEDED THE CUT-OFF SCORE ON NEST13.													
1a.	How much of a problem have you had getting your health insurance plan to cover your treatment?	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/> Yes <input type="checkbox"/> No
1b.	How often do you have to miss work or cut back on work due to your illness?	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/> Yes <input type="checkbox"/> No
1c.	How often do others have to increase their work hours or number of jobs to help pay for your medical care?	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/> Yes <input type="checkbox"/> No
1d.	How often do others have to miss work or cut back on work to care for you?	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/> Yes <input type="checkbox"/> No
1e.	How often do you face medical costs that cause you or another person to sell property, take out a loan or mortgage, or withdraw money from your retirement savings?	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/> Yes <input type="checkbox"/> No
<b>NEST13, ITEM 2:</b> ASK THE FOLLOWING QUESTION IF PATIENT'S SCORE EXCEEDED THE CUT-OFF SCORE ON NEST13.													
2a.	How much of a problem have you had with the choice of doctors, other health professionals, or clinics available to you?	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/> Yes <input type="checkbox"/> No

**NEST48 Interview Script**  
Patient

Item	Question for patient	0 = None of the time										10 = All of the time										Intervene?
<b>NEST13, ITEM 3:</b> ASK THE FOLLOWING QUESTIONS IF PATIENT'S SCORE EXCEEDED THE CUT-OFF SCORE ON NEST13.																						
<b>3a.</b>	How much help do you need with homemaking, such as preparing meals or keeping house?	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>								
<b>3b.</b>	How much help do you need with nursing care, such as taking medicine or having bandages changed?	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>								
<b>3c.</b>	How much help do you need with personal care, such as help with bathing or feeding?	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>								
<b>3d.</b>	In general, how active have you been in the last four weeks?	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>								
<b>NEST13, ITEM 4:</b> ASK THE FOLLOWING QUESTIONS IF PATIENT'S SCORE EXCEEDED THE CUT-OFF SCORE ON NEST13.																						
<b>4a.</b>	You are distressed by the thought that your life might end.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>								
<b>4b.</b>	You feel frightened and anxious.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>								
<b>4c.</b>	You feel anger or bitterness.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>								
<b>4d.</b>	You feel punished.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>								
<b>4e.</b>	Have you felt downhearted and blue?	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>								
<b>4f.</b>	You feel tranquil and serene.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>								
<b>4g.</b>	You feel prevented from doing what is necessary ... your family or close friends cannot accept ... your life may end.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>								
<b>NEST13, ITEM 5:</b> THIS IS NOT ADDRESSED BY NEST48. ASK FURTHER QUESTIONS USING THE ESAS INTERVIEW SCRIPT.																						
<b>NEST13, ITEM 6:</b> THIS IS NOT ADDRESSED BY NEST48. ASK FURTHER QUESTIONS USING THE ESAS INTERVIEW SCRIPT.																						

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Item	Question for patient	0 = None of the time										10 = All of the time										Intervene?	
<b>NEST13, ITEM 7:</b> ASK THE FOLLOWING QUESTIONS IF PATIENT'S SCORE EXCEEDED THE CUT-OFF SCORE ON NEST13.																							
7a.	How often is there someone who shows you love and affection?	0	1	2	3	4		6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>									
7b.	How often is there someone to confide in or talk to about your problems?	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>									
7c.	How often is there someone to share your most private fears and worries?	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>									
7d.	How often is there someone to talk with about your religious or spiritual feelings?	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>									
7e.	How often is there someone to have a good time with?	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>									
<b>NEST13, ITEM 8:</b> ASK THE FOLLOWING QUESTIONS IF PATIENT'S SCORE EXCEEDED THE CUT-OFF SCORE ON NEST13.																							
8a.	You have a spiritual or religious community that helps in your personal spiritual journey.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>									
8b.	Since your illness, you have become more spiritual or religious.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>									
8c.	How religious or spiritual do you consider yourself to be?	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>									
8d.	Prayer or meditation has helped me cope with this illness.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>									
8e.	During times of illness, my religious or spiritual beliefs have been strengthened.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>									
<b>NEST13, ITEM 9:</b> ASK THE FOLLOWING QUESTIONS IF PATIENT'S SCORE EXCEEDED THE CUT-OFF SCORE ON NEST13.																							
9a.	You try to help those around you prepare for the possibility of losing you.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>									

**NEST48 Interview Script**  
Patient

Item	Question for patient	10 = All of the time										Intervene?		
		0 = None of the time										Yes	No	
<b>9b.</b>	You are ready to pass on your former roles and for others to take them on.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>
<b>9c.</b>	You talk freely about the end of your life.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>
<b>9d.</b>	You feel relieved that life, and all its suffering, will end in the foreseeable future.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>
<b>NEST13, ITEM 10:</b> ASK THE FOLLOWING QUESTIONS IF PATIENT'S SCORE EXCEEDED THE CUT-OFF SCORE ON NEST13.														
<b>10a.</b>	Since your illness, you live life with a special sense of purpose.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>
<b>10b.</b>	When you imagine the end of your life, you want to make sure that you have finished an important project.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>
<b>10c.</b>	You feel you can make something good come from this illness.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>
<b>10d.</b>	You are more satisfied with yourself as a person now than you were before your illness.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>
<b>NEST13, ITEM 11:</b> ASK THE FOLLOWING QUESTIONS IF PATIENT'S SCORE EXCEEDED THE CUT-OFF SCORE ON NEST13.														
<b>11a.</b>	You feel that your doctor/nurse will help you through the medical system to get the medical care you need.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>
<b>11b.</b>	You feel that you are able to participate in decisions about your care.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>
<b>11c.</b>	You have complete trust in your doctor/nurse.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>



**NEST48 Interview Script**  
Patient

Item	Question for patient	10 = All of the time										Intervene?		
		0 = None of the time										Yes	No	
11d.	You feel that your doctor/nurse listens to what you have to say about your illness or medical treatment.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>
11e.	Your primary doctor tells you bad news in a sensitive and caring manner.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>
<b>NEST13, ITEM 12:</b> ASK THE FOLLOWING QUESTIONS IF PATIENT'S SCORE EXCEEDED THE CUT-OFF SCORE ON NEST13.														
12a.	Your doctor/nurse has given you a clear explanation of your treatment alternatives.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>
12b.	Your doctor/nurse has given you clear information about the risks and side effects of your treatment.	0	1	2	3	4	5	6	7	8	9	10	<input type="checkbox"/>	<input type="checkbox"/>

**IF THERE ARE CUT-OFF SCORES FROM NEST13 NECESSITATING ESAS, PROCEED TO ESAS. (SEE NEXT PAGE.)**

**NOTE: THE ESAS INTERVIEW OCCURS AFTER NEST48 AND ONLY IF THE PATIENT'S SCORE WAS GREATER THAN THE CUT-OFF SCORE FOR NEST13 ITEMS 5 AND/OR 6.**

Interviewer: These are some scales about symptoms that you may be having. Please identify the number that best describes how you are feeling. Like the previous questions you answered, we're asking you to rate your response on a scale between zero and 10, where zero is "no problem at all" and 10 is the "worst possible symptom."

		Worst possible pain									
No pain	0	1	2	3	4	5	6	7	8	9	10

Intervene?	
<input type="checkbox"/> Yes	<input type="checkbox"/> No

		Worst possible tiredness									
Not tired	0	1	2	3	4	5	6	7	8	9	10

Intervene?	
<input type="checkbox"/> Yes	<input type="checkbox"/> No

		Worst possible nausea									
Not nauseated	0	1	2	3	4	5	6	7	8	9	10

Intervene?	
<input type="checkbox"/> Yes	<input type="checkbox"/> No

		Worst possible depression									
Not depressed	0	1	2	3	4	5	6	7	8	9	10

Intervene?	
<input type="checkbox"/> Yes	<input type="checkbox"/> No

		Worst possible anxiety									
Not anxious	0	1	2	3	4	5	6	7	8	9	10

Intervene?	
<input type="checkbox"/> Yes	<input type="checkbox"/> No

Edmonton Symptom Assessment Scale (ESAS) Interview Script  
**Patient**

Not drowsy		Worst possible drowsiness								
0	1	2	3	4	5	6	7	8	9	10

<input type="checkbox"/> Yes	<input type="checkbox"/> No
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Best appetite		Worst possible appetite								
0	1	2	3	4	5	6	7	8	9	10

<input type="checkbox"/> Yes	<input type="checkbox"/> No
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Best feeling of well-being		Worst possible feeling of well-being								
0	1	2	3	4	5	6	7	8	9	10

<input type="checkbox"/> Yes	<input type="checkbox"/> No
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No shortness of breath		Worst possible shortness of breath								
0	1	2	3	4	5	6	7	8	9	10

<input type="checkbox"/> Yes	<input type="checkbox"/> No
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Other problem: \_\_\_\_\_

0	1	2	3	4	5	6	7	8	9	10

<input type="checkbox"/> Yes	<input type="checkbox"/> No
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