Memorial Sloan Kettering Cancer Center
IRB Number: 17-518 A(3)
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## Appendix Figure. Quality of Life survey

*This study is about understanding how you are doing since starting immunotherapy.*

*The survey is divided into 6 sections and allows us to compare how you are doing to other cancer survivors.*

*Thank you for your participation. Please read instructions for each section and complete to the best of your ability. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.*

### *Section 1: For the following questions, please circle the number from 1 to 4 that best applies to you.*

| | | Not at all | A Little | Quite a Bit | Very Much |
|---|---|---|---|---|---|
| 1. | Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase? | 1 | 2 | 3 | 4 |
| 2. | Do you have any trouble taking a long walk? | 1 | 2 | 3 | 4 |
| 3. | Do you have any trouble taking a short walk outside of the house? | 1 | 2 | 3 | 4 |
| 4. | Do you need to stay in bed or a chair during the day? | 1 | 2 | 3 | 4 |
| 5. | Do you need help with eating, dressing, washing yourself or using the toilet? | 1 | 2 | 3 | 4 |

| **During the past week:** | | **Not at all** | **A Little** | **Quite a Bit** | **Very Much** |
|---|---|---|---|---|---|
| 6. | Were you limited in doing either your work or other daily activities? | 1 | 2 | 3 | 4 |
| 7. | Were you limited in pursuing your hobbies or other leisure time activities? | 1 | 2 | 3 | 4 |
| 8. | Were you short of breath? | 1 | 2 | 3 | 4 |
| 9. | Have you had pain? | 1 | 2 | 3 | 4 |
| 10. | Did you need to rest? | 1 | 2 | 3 | 4 |
| 11. | Have you had trouble sleeping? | 1 | 2 | 3 | 4 |
| 12. | Have you felt weak? | 1 | 2 | 3 | 4 |

Memorial Sloan Kettering Cancer Center
IRB Number: 17-518 A(3)
Approval date: 05-Feb-2019

| | | | | | |
|---|---|---|---|---|---|
| 13. | Have you lacked appetite? | 1 | 2 | 3 | 4 |
| 14. | Have you felt nauseated? | 1 | 2 | 3 | 4 |
| 15. | Have you vomited? | 1 | 2 | 3 | 4 |
| 16. | Have you been constipated? | 1 | 2 | 3 | 4 |

| **During the past week:** | | **Not at all** | **A Little** | **Quite a Bit** | **Very Much** |
|---|---|---|---|---|---|
| 17. | Have you had diarrhea? | 1 | 2 | 3 | 4 |
| 18. | Were you tired? | 1 | 2 | 3 | 4 |
| 19. | Did pain interfere with your daily | 1 | 2 | 3 | 4 |
| 20. | Have you had difficulty in concentrating on things, like reading a newspaper or watching television? | 1 | 2 | 3 | 4 |
| 21. | Did you feel tense? | 1 | 2 | 3 | 4 |
| 22. | Did you worry? | 1 | 2 | 3 | 4 |
| 23. | Did you feel irritable? | 1 | 2 | 3 | 4 |
| 24. | Did you feel depressed? | 1 | 2 | 3 | 4 |
| 25. | Have you had difficulty remembering | 1 | 2 | 3 | 4 |
| 26. | Has your physical condition or medical treatment interfered with your family life? | 1 | 2 | 3 | 4 |
| 27. | Has your physical condition or medical treatment interfered with your social activities? | 1 | 2 | 3 | 4 |
| 28. | Has your physical condition or medical treatment caused you financial difficulties? | 1 | 2 | 3 | 4 |

**For the following questions please circle the number between 1 and 7 that best applies to you**

29. How would you rate your overall health during the past week?

1 2 3 4 5 6 7
Very poor Excellent

30. How would you rate your overall quality of life during the past week?

Memorial Sloan Kettering Cancer Center
IRB Number: 17-518 A(3)
Approval date: 05-Feb-2019

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Very poor | | | | | | Excellent |



***Section 2:*** ***By placing an "X" in one box in each group below, please indicate which statements best describe your own health state today.***

**31. Mobility**

I have no problems in walking about ☐1
I have some problems in walking about ☐2
I am confined to bed ☐3

**32. Self-Care**

I have no problems with self-care ☐1
I have some problems washing or dressing myself ☐2
I am unable to wash or dress myself ☐3

**33. Usual Activities** (*e.g. work, study, housework, family or leisure activities)*

I have no problems with performing my usual activities ☐1
I have some problems with performing my usual activities ☐2
I am unable to perform my usual activities ☐3

**34. Pain/Discomfort**

I have no pain or discomfort ☐1
I have moderate pain or discomfort ☐2
I have extreme pain or discomfort ☐3

**35. Anxiety/Depression**

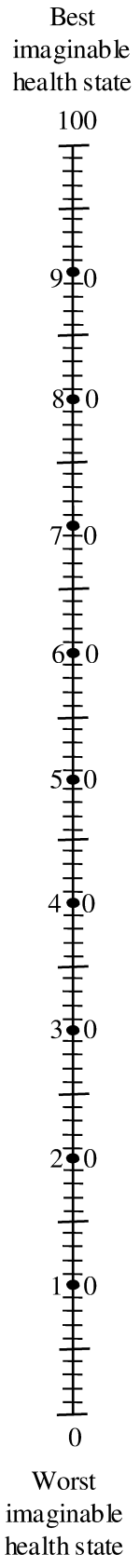
I am not anxious or depressed ☐1
I am moderately anxious or depressed ☐2
I am extremely anxious or depressed ☐3

Memorial Sloan Kettering Cancer Center
IRB Number: 17-518 A(3)
Approval date: 05-Feb-2019

36. To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

**Your own health state today**



Memorial Sloan Kettering Cancer Center
IRB Number: 17-518 A(3)
Approval date: 05-Feb-2019

***Section 3.*** **As individuals go through treatment for their cancer they sometimes experience different symptoms and side effects. For each question, please circle the response that best describes your experiences over the past 7 days…**

| | | | | | | |
|---|---|---|---|---|---|---|
| 37. | In the last 7 days, how OFTEN did you have ACHING JOINTS (SUCH AS ELBOWS, KNEES, SHOULDERS): | Never | Rarely | Occasionally | Frequently | Almost constantly |
| 38. | In the last 7 days, what was the SEVERITY of your ACHING JOINTS (SUCH AS ELBOWS, KNEES, SHOULDERS) at their WORST: | None | Mild | Moderate | Severe | Very severe |
| 39. | In the last 7 days, how much did ACHING JOINTS (SUCH AS ELBOWS, KNEES, SHOULDERS) INTERFERE with your usual or daily activities | Not at all | A little bit | Somewhat | Quite a bit | Very much |
| 40. | In the last 7 days, how OFTEN did you have ACHING MUSCLES: | Never | Rarely | Occasionally | Frequently | Almost constantly |
| 41. | In the last 7 days, what was the SEVERITY of your ACHING MUSCLES at their WORST: | None | Mild | Moderate | Severe | Very severe |
| 42. | In the last 7 days, how much did ACHING MUSCLES INTERFERE with your usual or daily activities: | Not at all | A little bit | Somewhat | Quite a bit | Very much |
| 43. | In the last 7 days, did you have any RASH: | Yes | No | | | |
| 44. | In the last 7 days, how OFTEN did you have a HEADACHE: | Never | Rarely | Occasionally | Frequently | Almost constantly |
| 45. | In the last 7 days, what was the SEVERITY of your HEADACHE at its WORST: | None | Mild | Moderate | Severe | Very severe |
| 46. | In the last 7 days, how much did your HEADACHE INTERFERE with your usual or daily activities: | Not at all | A little bit | Somewhat | Quite a bit | Very much |
| 47. | In the last 7 days, what was the SEVERITY of your ITCHY SKIN at its WORST: | None | Mild | Moderate | Severe | Very severe |
| 48. | In the last 7 days, what was the SEVERITY of your NUMBNESS OR TINGLING IN YOUR HANDS OR FEET at its WORST: | None | Mild | Moderate | Severe | Very severe |
| 49. | In the last 7 days, how much did NUMBNESS OR TINGLING IN YOUR HANDS OR FEET INTERFERE with your usual or daily activities: | Not at all | A little bit | Somewhat | Quite a bit | Very much |

Memorial Sloan Kettering Cancer Center
IRB Number: 17-518 A(3)
Approval date: 05-Feb-2019

| | | | | | | |
|---|---|---|---|---|---|---|
| 50. | In the last 7 days, how OFTEN did you experience any problems with your VISION? | Never | Rarely | Occasionally | Frequently | Almost constantly |
| 51. | In the last 7 days, how OFTEN did you have FEVER? | Never | Rarely | Occasionally | Frequently | Almost constantly |

52. Do you have concerns about any other symptoms? Please list below:

_____

_____

_____

_____

***Section 4.*** Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the <u>past 7 days</u>.**

| | | Not at all | A little bit | Somewhat | Quite a bit | Very much |
|---|---|---|---|---|---|---|
| 53. | I know that I have enough money in savings, retirement, or assets to cover the costs of my treatment. | 1 | 2 | 3 | 4 | 5 |
| 54. | My out-of-pocket medical expenses are more than I thought they would be. | 1 | 2 | 3 | 4 | 5 |
| 55. | I worry about the financial problems I will have in the future as a result of my illness or treatment. | 1 | 2 | 3 | 4 | 5 |
| 56. | I feel I have no choice about the amount of money I spend on care. | 1 | 2 | 3 | 4 | 5 |
| 57. | I am frustrated that I cannot work or contribute as much as I usually do. | 1 | 2 | 3 | 4 | 5 |
| 58. | I am satisfied with my current financial situation. | 1 | 2 | 3 | 4 | 5 |
| 59. | I am able to meet my monthly expenses. | 1 | 2 | 3 | 4 | 5 |
| 60. | I feel financially stressed. | 1 | 2 | 3 | 4 | 5 |
| 61. | I am concerned about keeping my job and | 1 | 2 | 3 | 4 | 5 |

Memorial Sloan Kettering Cancer Center
IRB Number: 17-518 A(3)
Approval date: 05-Feb-2019

| | | | | | | |
|---|---|---|---|---|---|---|
| | income, including work at home. | | | | | |
| 62. | My cancer or treatment has reduced my satisfaction with my present financial situation. | 1 | 2 | 3 | 4 | 5 |
| 63. | I feel in control of my financial situation. | 1 | 2 | 3 | 4 | 5 |

***Section 5.*** Please indicate your degree of agreement with each statement, based on how accurately it applies to your condition over the **past week**, where 1 indicates strongly disagree and 7, strongly agree.

| | | Strongly disagree | | | | | | Strongly agree |
|---|---|---|---|---|---|---|---|---|
| 64. | My motivation is lower when I am fatigued. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 65. | Exercise brings on my fatigue. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 66. | I am easily fatigued. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 67. | Fatigue interferes with my physical functioning. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 68. | Fatigue causes frequent problems for me. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 69. | My fatigue prevents sustained physical functioning. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 70. | Fatigue interferes with carrying out certain duties and responsibilities. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 71. | Fatigue is among my three most disabling symptoms. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

Memorial Sloan Kettering Cancer Center
IRB Number: 17-518 A(3)
Approval date: 05-Feb-2019

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 72. | Fatigue interferes with my work, family, or social life. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

***Section 6. Please list any problems (either from the questions you have just answered or any other problem you might have we did not ask about) that bother you. Then please tell us how much you agree with the following statement. (Can be repeated as needed)***

73. List the PROBLEM. (Free text)

_____

_____

_____

***(Can be repeated as needed)***

73a. Overall, how bothersome was managing PROBLEM 1 (automatically inserted from free text above) in the last month?

Not at all bothersome ☐
Bothers me a little ☐
Bothers me some ☐
Bothers me a lot ☐

73b. Do you have any other problems that are bothering you? Yes or No.
If yes, then prompted again to provide information on burden. When no, move on to the next question.

## *Section 7. Provider information*

In this section we are asking questions related to how many doctors outside of MSKCC that you see. Please list all doctors, nurse practitioners, and other care providers outside of MSKCC that you see. These questions will be repeated for as many providers you see outside of MSKCC.

74. Name your primary care doctor. _____

Memorial Sloan Kettering Cancer Center
IRB Number: 17-518 A(3)
Approval date: 05-Feb-2019

75. In the last 12 months, did you receive care from any doctors outside of MSKCC? Yes/No

If yes,

75a. What is this doctor's name?

75b. What type of provider is this doctor?

75c. What did you see this doctor for?

75d. How many visits did you have with this doctor in the last 12 months?

76. In the last 12 months, did you receive care outside of MSK from any nurse practitioner or physician assistant not affiliated with doctors you listed above? Yes/No

If yes,

76a. What is their name?

76b. What did you see this provider for?

76c. How many visits did you have with this provider in the last 12 months?

77. In the last 12 months, did you receive care from any other provider outside of MSKCC (e.g. physical therapist)? Yes/No

If yes,

77a. What is this provider's name?

77b. What did you see this provider for?

77c. How many visits did you have with this provider in the last 12 months?

## *Perception of communication between your providers*

78. Do your doctors outside of MSK receive information about your cancer or its treatment? Yes/No

78a. Provide any additional feedback on this topic.