**Lung Transplant Health-Related Quality of Life
(LT-QOL) Survey**

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LT-QOL Scoring Information

**NOTE**: We recommend that LT-QOL users be familiar with the publication that describes its development, to understand the implications of the scoring options.

**Direction of scoring LT-QOL scales**: All LT-QOL scales are scored so that higher scores indicate higher levels of the labeled scale. All but one scale are scored so that higher scores indicate worse health; the *General quality of life* scale is scored so that higher scores indicated better quality of life. This is done to convey the meaning of the original construct based on how the questions were asked.

**Calculating scores**: Scale scores for each respondent are calculated as the mean of their responses to the corresponding non-missing items (i.e., item responses are averaged, not summed). This results in scale scores with a possible range of 1-5 and allows for individual scale scores to be calculated whenever at least one item per scale has a valid response.

The table below summarizes scoring rules for each scale.

**LT-QOL Scoring Rules**

| **CATEGORY** | **Second-order scales**First-order scales | # of items | Survey item number | Possible range  |
| --- | --- | --- | --- | --- |
| **SYMPTOMS** | **Pulmonary symptoms**  | 7 | 1-7 | 1-5 |
|  | Shortness of breath  | 3 | 1-2, 6 | 1-5 |
|  | Cough  | 4 | 3-5, 7 | 1-5 |
|  | **GI symptoms**  | 11 | 8-18 | 1-5 |
|  |  Eating/aspiration problems  | 3 | 8-10 | 1-5 |
|  | Lack of interest in eating  | 3 | 11-12 | 1-5 |
|  | Upper GI symptoms  | 3 | 13-15 | 1-5 |
|  | Lower GI symptoms | 2 | 16-18 | 1-5 |
|  | **Neuromuscular symptoms**  | 4 | 19-22 | 1-5 |
| **HEALTH PERCEPTIONS** | **Treatment burden**  | 3 | 23-25 | 1-5 |
|  | **Worry about future health**  | 5 | 26-30 | 1-5 |
| **FUNCTIONING** | **Cognitive limitations** | 6 | 44-49 | 1-5 |
|  | **Sexual problems** | 3 | 56-58 | 1-5 |
| **WELL-BEING** | **Anxiety/depression** | 13 | 31-43 | 1-5 |
|  | Anxiety | 7 | 31-37 | 1-5 |
|  | Depressive symptoms  | 6 | 38-43 | 1-5 |
|  | **Health distress** | 4 | 50-55 | 1-5 |
|  | **General quality of life\*** | 2 | 59-60 | 1-5 |

\*For General quality of life scale, higher scores denote better health. For all other scales,

higher scores denote worse health

**Date: ­­­\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Subject Number: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**

**Lung Transplant Quality of Life (LT-QOL) Survey**

**We very much appreciate you participating in our study.**

**Please turn the page to begin the survey.**

**Thinking back over the past 4 weeks, how often did you experience any of the following when you were NOT having a lung infection or rejection?...**

|  | Not at all | Only when I had an infection | A few days a month | Several days a week | Almost every day |
| --- | --- | --- | --- | --- | --- |
| 1. I had shortness of breath  | 1 | 2 | 3 | 4 | 5 |
| 2. I felt tightness in my chest | 1 | 2 | 3 | 4 | 5 |
| 3. I coughed | 1 | 2 | 3 | 4 | 5 |
| 4. I brought up phlegm (sputum) | 1 | 2 | 3 | 4 | 5 |
| 5. I had episodes of wheezing  | 1 | 2 | 3 | 4 | 5 |
|  | Every day | Nearly every day | 3 or 4 days/week | 1 or 2 days/week | None |
| 6. Over the last 3 months, how many good days (with few lung/respiratory problems) have you had? | 1 | 2 | 3 | 4 | 5 |
|  |  |  |  |  |  |
|  | No episodes | 1 episode | 2 episodes | 3 episodes | More than 3 episodes |
| 7. During the last 3 months, how many severe or very unpleasant episodes of lung/respiratory problems have you had? | 1 | 2 | 3 | 4 | 5 |

| **Below is a list of symptoms and conditions you may have experienced. Over the past 4 weeks, how often have you experienced the following?**  | Never | Once or twice | A few times | Fairly often | Very often |
| --- | --- | --- | --- | --- | --- |
| 8. I had trouble swallowing food  | 1 | 2 | 3 | 4 | 5 |
| 9. I had difficulty swallowing liquids  | 1 | 2 | 3 | 4 | 5 |
| 10. I have choked when I swallowed  | 1 | 2 | 3 | 4 | 5 |
| 11. I have been bothered in the way food tastes. | 1 | 2 | 3 | 4 | 5 |
| 12. I had a poor appetite | 1 | 2 | 3 | 4 | 5 |
| 13. I had nausea | 1 | 2 | 3 | 4 | 5 |
| 14. I had discomfort or pain in my stomach area | 1 | 2 | 3 | 4 | 5 |
| 15. I had swelling or cramps in my stomach area | 1 | 2 | 3 | 4 | 5 |
| 16. I had constipation | 1 | 2 | 3 | 4 | 5 |
| 17. I had diarrhea | 1 | 2 | 3 | 4 | 5 |
| 18. I have been afraid to be far from a toilet | 1 | 2 | 3 | 4 | 5 |
| 19. I had shaky hands | 1 | 2 | 3 | 4 | 5 |
| 20. My leg muscles felt weak | 1 | 2 | 3 | 4 | 5 |
| 21. I had numbness and tingling in my hands or feet | 1 | 2 | 3 | 4 | 5 |
| 22. I felt discomfort in my hands or feet (pain, cramping, burning, etc.) | 1 | 2 | 3 | 4 | 5 |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **These questions ask about your treatment regimen (medications, clinic visits and tests like x-rays, bronchoscopies) over the past 4 weeks.**  | Not at all | A little bit | Some-what | Quite a bit | Very much |
| 23. The effects of the treatment have been worse than I had imagined. | 1 | 2 | 3 | 4 | 5 |
| 24. To what extent did your treatments (including medications) make your daily life more difficult? | 1 | 2 | 3 | 4 | 5 |
| 25. How difficult was it for you to do your treatments (including medications) each day? | 1 | 2 | 3 | 4 | 5 |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Over the past 4 weeks, to what extent does each statement apply to you?**  | Not at all | A little bit | Some-what | Quite a bit | Very much |
| 26. I worry that my lung transplant will not work or that I will get rejection | 1 | 2 | 3 | 4 | 5 |
| 27. I worry about getting infections  | 1 | 2 | 3 | 4 | 5 |
| 28. Because of my lung transplant, I had difficulty planning for the future  | 1 | 2 | 3 | 4 | 5 |
| 29. I worried that my health will get worse  | 1 | 2 | 3 | 4 | 5 |
| 30. I felt uncertain about my future health  | 1 | 2 | 3 | 4 | 5 |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Over the past 4 weeks, how often have you been bothered by the following problems?** | Never | Once or twice | A few times | Fairly often | Very often |
| 31. Feeling nervous, anxious or on edge  | 1 | 2 | 3 | 4 | 5 |
| 32. Not being able to stop or control worrying  | 1 | 2 | 3 | 4 | 5 |
| 33. Worrying too much about different things  | 1 | 2 | 3 | 4 | 5 |
| 34. Trouble relaxing | 1 | 2 | 3 | 4 | 5 |
| 35. Being so restless that it was hard to sit still  | 1 | 2 | 3 | 4 | 5 |
| 36. Becoming easily annoyed or irritable  | 1 | 2 | 3 | 4 | 5 |
| 37. Feeling afraid as if something awful might happen  | 1 | 2 | 3 | 4 | 5 |
| **These questions are about how you feel and how things have been with you. Over thepast 4 weeks, how often…** | Never  | Once or twice | A few times | Fairly often | Very often |
| 38. Has feeling depressed interfered with what you usually do?  | 1 | 2 | 3 | 4 | 5 |
| 39. Did you feel depressed?  | 1 | 2 | 3 | 4 | 5 |
| 40. Were you moody or brood about things?  | 1 | 2 | 3 | 4 | 5 |
| 41. Were you in low or very low spirits?  | 1 | 2 | 3 | 4 | 5 |
| 42. Have you felt downhearted and depressed? | 1 | 2 | 3 | 4 | 5 |
|  |  |  |  |  |  |
|  | Not at all | A little  | Some-what | Very  | Extremely  |
| 43. How depressed (at its worst) have you felt? | 1 | 2 | 3 | 4 | 5 |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Over the past 4 weeks, how much of the time did you…**  | None of the time | A little of the time | Some of the time | Most of the time | All of the time |
| 44. Have difficulty reasoning and solving problems; for example, making plans, making decisions, learning new things?  | 1 | 2 | 3 | 4 | 5 |
| 45. Have difficulty doing activities involving concentration and thinking?  | 1 | 2 | 3 | 4 | 5 |
| 46. Become confused and start several actions at a time?  | 1 | 2 | 3 | 4 | 5 |
| 47. Forget, for example things that happened recently, where you put things, appointments? | 1 | 2 | 3 | 4 | 5 |
| 48. Have trouble keeping your attention on any activity for long? | 1 | 2 | 3 | 4 | 5 |
| 49. React slowly to things that were said or done? | 1 | 2 | 3 | 4 | 5 |

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **How often in the past 4 weeks….** | Never | Once or twice | A few times | Fairly often |  Very often |
| 50. Were you frustrated about your health?  | 1 | 2 | 3 | 4 | 5 |
| 51. Did you feel weighed down by your health problems? | 1 | 2 | 3 | 4 | 5 |
| 52. Were you discouraged by your health problems?  | 1 | 2 | 3 | 4 | 5 |
| 53. Did you feel despair over your health problems? | 1 | 2 | 3 | 4 | 5 |
| 54. Were you afraid because of your health? | 1 | 2 | 3 | 4 | 5 |
| 55. Was your health a worry in your life?  | 1 | 2 | 3 | 4 | 5 |

**The next questions are about the way health problems might interfere with your sex life. These questions are personal but important in understanding how health problems might affect people’s lives.**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **How much of a problem was each of the following during the past 4 weeks?**  | Not at all | A little bit | Some-what | Quite a bit | Very much |
| 56. Lack of sexual interest? | 1 | 2 | 3 | 4 | 5 |
| 57. Unable to relax and enjoy sex? | 1 | 2 | 3 | 4 | 5 |
| 58. Difficulty in becoming sexually aroused? | 1 | 2 | 3 | 4 | 5 |

**The last two questions are about your life in general.**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Over the past 4 weeks, to what extent does each statement apply to you?**  | Not at all | A little bit | Some-what | Quite a bit | Very much |
| 59. I am able to enjoy life. | 1 | 2 | 3 | 4 | 5 |
| 60. I am content with the quality of my life right now.  | 1 | 2 | 3 | 4 | 5 |

**You have reached the end of the survey. Thank you for your participation.**

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