

# 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	<u>Second-order scales</u>	# of items	Survey item number	Possible range
	First-order scales			
SYMPTOMS	<u>Pulmonary symptoms</u>	<u>7</u>	<u>1-7</u>	1-5
	Shortness of breath	3	1-2, 6	1-5
	Cough	4	3-5, 7	1-5
	<u>GI symptoms</u>	<u>11</u>	<u>8-18</u>	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
	<u>Neuromuscular symptoms</u>	4	19-22	1-5
	HEALTH PERCEPTIONS	<u>Treatment burden</u>	3	23-25
<u>Worry about future health</u>		5	26-30	1-5
FUNCTIONING	<u>Cognitive limitations</u>	6	44-49	1-5
	<u>Sexual problems</u>	3	56-58	1-5
WELL-BEING	<u>Anxiety/depression</u>	<u>13</u>	<u>31-43</u>	1-5
	Anxiety	7	31-37	1-5
	Depressive symptoms	6	38-43	1-5
	<u>Health distress</u>	4	50-55	1-5
	<u>General quality of life*</u>	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 <u>last 3 months</u> , 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 <u>last 3 months</u> , 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



<b>These questions ask about your treatment regimen (medications, clinic visits and tests like x-rays, bronchoscopies) over the <u>past 4 weeks</u>.</b>	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
<b>Over the <u>past 4 weeks</u>, to what extent does each statement apply to you?</b>	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
<b>Over the <u>past 4 weeks</u>, how often have you been bothered by the following problems?</b>	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 the past 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



<b>How often in the past 4 weeks....</b>	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.**

<b>How much of a problem was each of the following during the <u>past 4 weeks</u>?</b>	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.**

<b>Over the <u>past 4 weeks</u>, to what extent does each statement apply to you?</b>	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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