Date: _____

Name: _____

UCSF Medical Center
Lung Transplant

Improving Health Related Quality of Life Outcomes in Lung Transplantation:

A multicenter study between the UC San Francisco, the University of Pennsylvania, and Columbia University Lung Transplant Programs

The goal of this survey is to understand how your health impacts your ability to do your day to day activities and your quality of life.

We at the UCSF, University of Pennsylvania, and Columbia University Lung Transplant Research Programs truly appreciate your participation in this study!

Please make every effort to answer each and every question in the survey. There are no wrong answers, so just choose the answer that best describes your feelings or thoughts today.

Please turn the page to begin the survey.

1. In general, would you say your health is:

☐	☐	☐	☐	☐
Excellent	Very Good	Good	Fair	Poor

The following items are about activities you might do during a typical day. Does your health now limit you in these activities, and if so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
2. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling	☐	☐	☐
3. Climbing several flights of stairs	☐	☐	☐

During the past 4 weeks, have you had any of the following problems with your work *or* other regular daily activities as a result of your physical health?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
4. Accomplished less than you would like	☐	☐	☐	☐	☐
5. Were limited in the kinds of work *or* other activities you could do	☐	☐	☐	☐	☐

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed and anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
6. Accomplished less than you would like	☐	☐	☐	☐	☐
7. Did work or other activities less carefully than usual	☐	☐	☐	☐	☐

8. During the past four weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

☐	☐	☐	☐	☐
Not at All	Slightly	Moderately	Quite a Bit	Extremely

How much of the time in the past 4 weeks…	All of the time	Most of the time	Some of the time	A little of the time	None of the time
9. Have you felt calm and peaceful?	☐	☐	☐	☐	☐
10. Did you have a lot of energy?	☐	☐	☐	☐	☐
12. Have you felt downhearted and blue?	☐	☐	☐	☐	☐

13. During the past four weeks, how much of the time has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors or groups?

☐	☐	☐	☐	☐
All of the time	Most of the time	Some of the time	A little of the time	None of the time

These questions are about how your health affects your ability to do things that are important to you. Please indicate **how much difficulty** you have had performing each of these activities **over the past month given your overall health now.**

If you do not perform an activity:

- because of your health, then check "**Unable to do at all**".
- because it is not important to you or for reasons other than your health, then check "**Does not apply to me**".

How much difficulty have you had performing the following activities?	None	Some	A lot	Unable to do at all	Does not apply to me
14. Taking care of your basic needs, such as bathing, getting dressed or taking care of personal hygiene	☐	☐	☐	☐	☐
15. Preparing meals and cooking	☐	☐	☐	☐	☐
16. Doing light work around the house, such as dusting or laundry	☐	☐	☐	☐	☐
17. Doing heavier housework, such as vacuuming, changing sheets or cleaning floors	☐	☐	☐	☐	☐
18. Walking or getting around INSIDE your home	☐	☐	☐	☐	☐
19. Walking OUTSIDE your home, just to get around to places you go on a regular basis	☐	☐	☐	☐	☐
20. Getting around your community by car or by public transportation	☐	☐	☐	☐	☐
21. Going to social events, parties or celebrations	☐	☐	☐	☐	☐
22. Visiting friends or family members in THEIR homes	☐	☐	☐	☐	☐
23. Having friends or family members visit you in YOUR home	☐	☐	☐	☐	☐
24. Participating in leisure activities IN YOUR HOME, i.e. reading, watching television, or listening to music	☐	☐	☐	☐	☐
25. Participating in leisure activities OUTSIDE your home, such as playing cards or bingo, or going to movies, club meetings, or restaurants	☐	☐	☐	☐	☐
26. Participating in physical recreational activities, such as walking for exercise, playing golf, bicycling, swimming, or water aerobics	☐	☐	☐	☐	☐
27. Traveling out of town	☐	☐	☐	☐	☐
28. Working at a job for pay	☐	☐	☐	☐	☐

29. How much did you weigh one year ago?:_____(pounds)

30. During the past year, have you lost 10 or more pounds?: Yes ☐ No ☐ Don't know ☐

a) If yes, was it: intentional ☐ unintentional ☐

b) How did you lose the weight? _____

How often in the last week did you feel that…

	Rarely or none of the time (<1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of the time (3-4 days)	Most of the time (5-7 days)
31. Everything I did was an effort	☐	☐	☐	☐
32. I could not "get going"	☐	☐	☐	☐

The next questions ask about your attitudes and general outlook on life over the past week.	Yes	No
33. Are you basically satisfied with your life?	☐	☐
34. Have you dropped many of your activities and interests?	☐	☐
35. Do you feel that your life is empty?	☐	☐
36. Do you often get bored?	☐	☐
37. Are you in good spirits most of the time?	☐	☐
38. Are you afraid that something bad is going to happen to you?	☐	☐
39. Do you feel happy most of the time?	☐	☐
40. Do you often feel helpless?	☐	☐
41. Do you prefer to stay at home, rather than going out and doing new things?	☐	☐
42. Do you feel you have more problems with memory than most?	☐	☐
43. Do you think it is wonderful to be alive now?	☐	☐
44. Do you feel pretty worthless the way you are now?	☐	☐
45. Do you feel full of energy?	☐	☐
46. Do you feel your situation is hopeless?	☐	☐
47. Do you think that most people are better off than you?	☐	☐

Please answer the following questions about your activity level.	Yes	No
48. Can you take care of yourself (eating, dressing, bathing, or using the toilet)?	☐	☐
49. Can you walk indoors such as around your house?	☐	☐
50. Can you walk a block or two on level ground?	☐	☐
51. Can you climb a flight of stairs or walk up a hill?	☐	☐
52. Can you run a short distance?	☐	☐
53. Can you do light work around the house like dusting or washing dishes?	☐	☐
54. Can you do moderate work around the house like vacuuming, sweeping floors, or carrying in groceries?	☐	☐
55. Can you do heavy work around the house like scrubbing floors or lifting and moving furniture?	☐	☐
56. Can you do yardwork like raking leaves, weeding, or pushing a power mower?	☐	☐

57. Can you have sexual relations?	☐	☐
58. Can you participate in moderate recreational activities like golf, bowling, dancing, doubles tennis, or throwing a baseball or football?	☐	☐
59. Can you participate in strenuous sports like swimming, singles tennis, football, basketball, or skiing?	☐	☐

For the following questions, please answer yes or no.
If you do not perform the activity for reasons other than your health or the question is not applicable to you, please check "Does not apply".

	No	Yes	Does not apply
60. Do you suffer from coughing attacks during the day?	☐	☐	☐
61. Because of your breathing problems, do you often feel restless?	☐	☐	☐
62. Do you suffer from breathing problems as a result of exposure to strong smells, cigarette smoke, or perfume?	☐	☐	☐
63. Do you feel breathless while trying to sleep?	☐	☐	☐
64. Do you worry that drugs that you will have to take because of your breathing problems will have long-term effects on your health?	☐	☐	☐
65. Does getting emotionally upset make your breathing problems worse?	☐	☐	☐
66. Because of your breathing problems, do you suffer from breathlessness when you laugh?	☐	☐	☐
67. Because of your breathing problems, do you often feel impatient?	☐	☐	☐
68. Because of your breathing problems, do you feel that you cannot enjoy a full life?	☐	☐	☐
69. Do you feel drained after a cold because of your breathing problems?	☐	☐	☐
70. Do you have feelings of chest heaviness?	☐	☐	☐
71. Do you worry much about your breathing problems?	☐	☐	☐
72. Is your partner bothered by your breathing problems?	☐	☐	☐

For the following questions, please answer yes or no.

- If you cannot perform the activity mentioned because of your breathing problems, please check that you are "Unable".
- If you do not perform the activity for reasons other than your health or the question is not applicable to you, please check "Does not apply".

	No	Yes	Unable	Does not apply
73. Because of your breathing problems, do you feel breathless when gardening?	☐	☐	☐	☐
74. Do you worry when going to a friend's house that there might be something there that will set off an attack of breathing problems?	☐	☐	☐	☐
75. Because of your breathing problems, are there times when you have difficulty getting around the house?	☐	☐	☐	☐

76. Because of your breathing problems, do you suffer from breathlessness carrying out activities at work?	☐	☐	☐	☐
	No	Yes	Unable	Does not apply
77. Do you feel breathless walking upstairs because of your breathing problems?	☐	☐	☐	☐
78. Because of your breathing problems, do you suffer from breathlessness doing housework?	☐	☐	☐	☐
79. Because of your breathing problems, do you go home sooner than others after a night out?	☐	☐	☐	☐

Thinking back over the <u>past 4 weeks</u>, 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
80. I had shortness of breath	☐	☐	☐	☐	☐
81. I felt tightness in my chest	☐	☐	☐	☐	☐
82. I coughed	☐	☐	☐	☐	☐
83. I brought up phlegm (sputum)	☐	☐	☐	☐	☐
84. I had episodes of wheezing	☐	☐	☐	☐	☐

	None	1 or 2 days/week	3 or 4 days/week	Nearly every day	Every day
85. Over the <u>last 3 months,</u> how many good days (with few lung/respiratory problems) have you had?	☐	☐	☐	☐	☐

	No episodes	1 episode	2 episodes	3 episodes	More than 3 episodes
86. During the <u>last 3 months</u>, how many severe or very unpleasant episodes of lung/respiratory problems have you had?	☐	☐	☐	☐	☐

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
87. I had trouble swallowing food	☐	☐	☐	☐	☐
88. I had difficulty swallowing liquids	☐	☐	☐	☐	☐
89. I have choked when I swallowed	☐	☐	☐	☐	☐
90. I have been bothered in the way food tastes.	☐	☐	☐	☐	☐
91. I had a poor appetite	☐	☐	☐	☐	☐
92. I had nausea	☐	☐	☐	☐	☐
93. I had discomfort or pain in my stomach area	☐	☐	☐	☐	☐
94. I had swelling or cramps in my stomach area	☐	☐	☐	☐	☐
95. I had constipation	☐	☐	☐	☐	☐
96. I had diarrhea	☐	☐	☐	☐	☐
97. I have been afraid to be far from a toilet	☐	☐	☐	☐	☐
98. I had shaky hands	☐	☐	☐	☐	☐
99. My leg muscles felt weak	☐	☐	☐	☐	☐
100. I had numbness and tingling in my hands or feet	☐	☐	☐	☐	☐
101. I felt discomfort in my hands or feet (pain, cramping, burning, etc.)	☐	☐	☐	☐	☐

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
102. The effects of the treatment have been worse than I had imagined.	☐	☐	☐	☐	☐
103. To what extent did your treatments (including medications) make your daily life more difficult?	☐	☐	☐	☐	☐
104. How difficult was it for you to do your treatments (including medications) each day?	☐	☐	☐	☐	☐

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
105. I worry that my lung transplant will not work or that I will get rejection	☐	☐	☐	☐	☐
106. I worry about getting infections	☐	☐	☐	☐	☐
107. Because of my lung transplant, I had difficulty planning for the future	☐	☐	☐	☐	☐
108. I worried that my health will get worse	☐	☐	☐	☐	☐
109. I felt uncertain about my future health	☐	☐	☐	☐	☐

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
110. Feeling nervous, anxious or on edge	☐	☐	☐	☐	☐
111. Not being able to stop or control worrying	☐	☐	☐	☐	☐
112. Worrying too much about different things	☐	☐	☐	☐	☐
113. Trouble relaxing	☐	☐	☐	☐	☐
114. Being so restless that it was hard to sit still	☐	☐	☐	☐	☐
115. Becoming easily annoyed or irritable	☐	☐	☐	☐	☐
116. Feeling afraid as if something awful might happen	☐	☐	☐	☐	☐

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
117. Has feeling depressed interfered with what you usually do?	☐	☐	☐	☐	☐
118. Did you feel depressed?	☐	☐	☐	☐	☐
119. Were you moody or brood about things?	☐	☐	☐	☐	☐
120. Were you in low or very low spirits?	☐	☐	☐	☐	☐
121. Have you felt downhearted and depressed?	☐	☐	☐	☐	☐

	Not at all	A little	Some-what	Very	Extremely
122. How depressed (at its worst) have you felt?	☐	☐	☐	☐	☐

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
123. Have difficulty reasoning and solving problems; for example, making plans, making decisions, learning new things?	☐	☐	☐	☐	☐
124. Have difficulty doing activities involving concentration and thinking?	☐	☐	☐	☐	☐
125. Become confused and start several actions at a time?	☐	☐	☐	☐	☐
126. Forget, for example things that happened recently, where you put things, appointments?	☐	☐	☐	☐	☐
127. Have trouble keeping your attention on any activity for long?	☐	☐	☐	☐	☐
128. React slowly to things that were said or done?	☐	☐	☐	☐	☐

How often in the past 4 weeks….	Never	Once or twice	A few times	Fairly often	Very often
129. Were you frustrated about your health?	☐	☐	☐	☐	☐
130. Did you feel weighed down by your health problems?	☐	☐	☐	☐	☐
131. Were you discouraged by your health problems?	☐	☐	☐	☐	☐
132. Did you feel despair over your health problems?	☐	☐	☐	☐	☐
133. Were you afraid because of your health?	☐	☐	☐	☐	☐
134. Was your health a worry in your life?	☐	☐	☐	☐	☐

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
135. Lack of sexual interest?	☐	☐	☐	☐	☐
136. Unable to relax and enjoy sex?	☐	☐	☐	☐	☐
137. Difficulty in becoming sexually aroused?	☐	☐	☐	☐	☐

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
138. I am able to enjoy life.	☐	☐	☐	☐	☐
139. I am content with the quality of my life right now.	☐	☐	☐	☐	☐

What is your race?

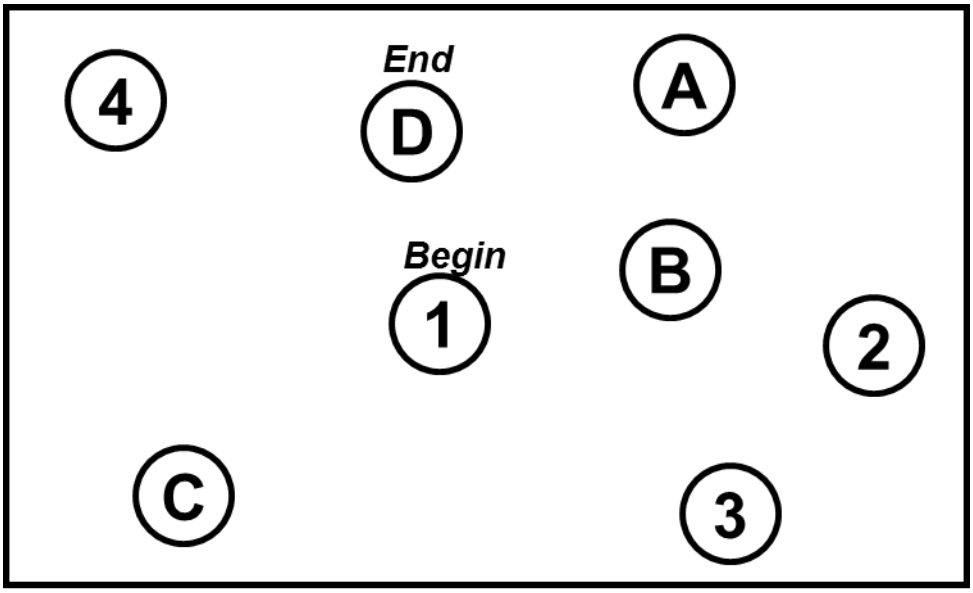
☐ White
☐ Black/African American
☐ Asian
☐ Native Hawaiian/ Other Pacific Islander
☐ American Indian/ Alaska Native
☐ Other: please specify _____

What is your ethnicity?

☐Hispanic/Latino
☐Not Hispanic/Latino

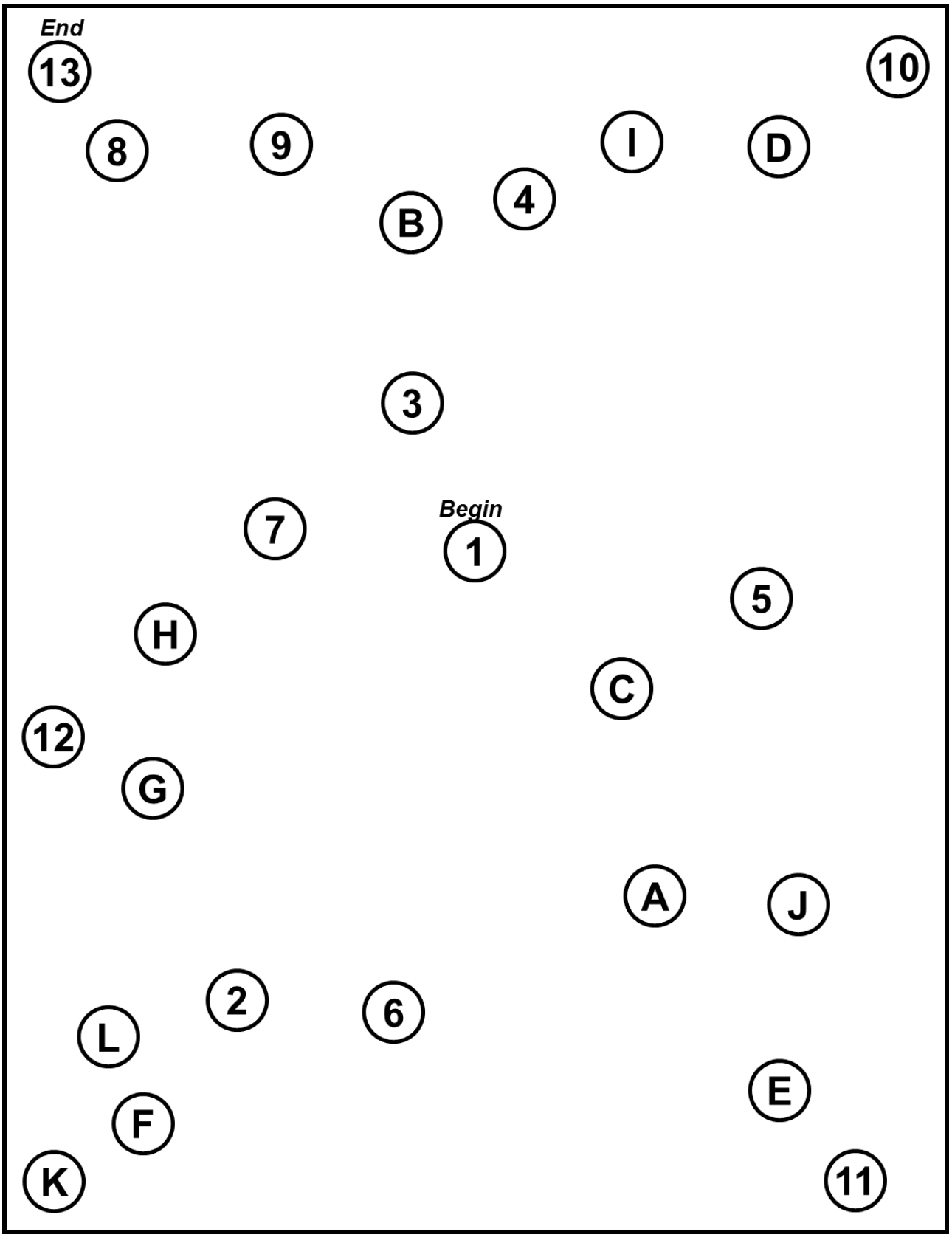
Please wait and finish with your study coordinator

SAMPLE



Instructions:

- Connect the circles as quickly as possible without lifting the pen or pencil from the paper
- You will be timed as you draw a line connecting the circles in ascending pattern, alternating between the numbers and letters (i.e., 1-A-2-B-3-C, etc.)
- The time starts when you start drawing the “trail”
- If you make an error, it will be pointed out to you immediately
- Errors only affect your score in that the correction of errors is included in the completion time for the task



Time (seconds): _____