Scoring Instructions for the Lung Information Needs Questionnaire (LINQ)

The questionnaire measures the extent to which the patient needs more information, as perceived by the patient and clinician. It is scored to produce an overall score and 6 domain scores.

The questionnaire is reproduced on the following pages with the scores indicated against the different response options.

2. To produce the domain scores for all the domain scores except Smoking, add up the scores against the options ticked for the following question numbers.

<table>
<thead>
<tr>
<th>Question numbers</th>
<th>Domain</th>
<th>Score range</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 – 4</td>
<td>Disease knowledge</td>
<td>0 – 4</td>
</tr>
<tr>
<td>5 – 7</td>
<td>Medicines</td>
<td>0 – 5</td>
</tr>
<tr>
<td>8 – 9</td>
<td>Self-management</td>
<td>0 – 6</td>
</tr>
<tr>
<td>13 – 15</td>
<td>Exercise</td>
<td>0 – 5</td>
</tr>
<tr>
<td>16</td>
<td>Diet</td>
<td>0 – 2</td>
</tr>
</tbody>
</table>

For the smoking domain, if the patient scores 0 for question 10 (i.e., is no longer smoking) then the score for that domain is 0 irrespective of response to question 11 or 12. If the patient scores 1 for question 10, then add scores for questions 10 – 12, i.e.,

10 – 12 Smoking 0 – 3

To produce the overall score, add up the scores for all 6 domains:
The minimum score (low information needs) is 0
The maximum score (high information needs) is 25

Note: high scores indicate high information needs

Note: Length of time to completion: approximately 6 minutes
1. Do you know the name of your lung disease?

Yes 0

No 1

2. Has a doctor or nurse told you how this disease affects your lungs?

YES 0

NO 1

3. Has a doctor or nurse told you what is likely to happen in the future?

YES 0

NO 1

4. Which of the following statements best describes what will happen to you over the next few years? **TICK ONE ONLY**

I will get worse 0

Now that my disease is being treated, I will probably stay the same 1

Now that my disease is being treated, I will probably get better 1

I have no idea 1
5 Has a doctor or nurse explained the reason for taking your inhalers or medicines?

YES 0
NO 1

6 Do you try to take your inhalers or medicines exactly as you have been instructed by a doctor or nurse?

YES 0
NO 1

7 Are you satisfied with the information doctors and nurses have given you about your inhalers or medicines? **TICK ONE ONLY**

I understand everything I need to know 0
I understand what I have been told but I would like to know more 1
I am slightly confused about my medicines 2
I am very confused about my medicines 3

8 What sentence best describes what you have been told to do if your breathing gets worse (e.g., take two puffs instead of one)? **TICK ONE ONLY**

I have been told what to do and the doctor/nurse has given me written instructions 0
I have been told but it is not written on paper 1
I haven't been told but I know what to do 2
I haven't been told and I don't know what to do 3
9 Have you been told when you should call an **ambulance** if your breathing worsens?

**TICK ONE ONLY**

- I have been told what to do and the doctor/nurse has given me written instructions
- I have been told but it isn't written on paper
- I haven't been told but I know what to do
- I haven't been told and I am uncertain when an ambulance should be called

10 What best describes you?

**TICK ONE ONLY**

- Never smoked (go to question 13)
- Used to smoke but don't now (go to question 13)
- Still smoking (go to question 11)

11 Has a doctor or nurse advised you to give up smoking?

- YES
- NO

12 Has a doctor or nurse offered to help you to give up smoking?

(e.g., given you nicotine gum or patches referral to a Smoking Cessation clinic)?

- YES
- NO
13  Have you been told by a doctor or nurse to try to do some physical activity (e.g., walking, brisk walking and other forms of exercise)?

- **YES** 0
- **NO** 1

14  Has a doctor or nurse told you *how much* physical activity (e.g., walking, brisk walking and other forms of exercise) you should do?

- Yes and I know what to do 0
- Yes but I am unsure what to do 1
- Yes but I am unable to do it 1
- No 2

15  How much physical activity do you do?

- I push myself as much as I can 0
- I make an effort 1
- As little as possible 2

16  What have doctors or nurses told you about your diet or eating?  

(please tick *all* that apply)

- Eat several *small meals per day* 0
  "(e.g., 6 small meals per day instead of 3 large ones)"
- Lose or gain weight 1
- Eat healthy food 1
- Nothing 2
17 Have you any questions or comments about your lung disease? 
"If so, write them in the space below"

(not scored)

18 Sex (delete one) Male = 0 

Female = 1

(to be coded for demographic purpose but not part of the LINQ)

19 In which year were you born? 19 _ _

(to be coded for demographic purpose but not part of the LINQ – code actual date)