

APPENDIX

CONCEPT ELICITATION & COGNITIVE INTERVIEW GUIDE

CONCEPT ELICITATION OF Interstitial Lung Disease Symptoms, Impacts and Progression of Disease

(UP TO 30 MIN)

Let's get started.

1. You qualified for this study because you have a medical condition that affects your lungs. What do you call this condition?
 - Are there any other terms that your doctor has used to describe your medical condition?
2. How long has it been since you were first diagnosed with [lung condition]?
3. Thinking back to before you were diagnosed with [lung condition], what were the first signs that something was wrong? What symptoms were you feeling?
4. What made you decide you needed to go see a doctor?
5. Tell me about the day you received your diagnosis.
 - Did you have to go to many physicians before getting a diagnosis, or were you diagnosed the first time you saw a physician for your lung problem?
 - If not, how long did it take from that first visit with a doctor until the doctor was able to tell you exactly what you had?
 - Did your diagnosis ever change after that first visit? (i.e. they told you had one kind of lung condition, then later they told you had something different).
 - What did the doctor tell you about [lung condition] Was there anything that your doctor told you that day that you remember being very helpful? Anything that was not very helpful?
 - Has your doctor been your only source of information about [lung condition]? Or did you look for other ways to learn about your illness? Please describe
 - Did you see multiple doctors before receiving your diagnosis?
6. Do you have any symptoms today from [your lung condition]? If so, can you describe them?

Sign/Symptoms Currently Experiencing	Spontaneously mentioned?	Probed?
1. Cough		
2. Shortness of Breath/Dyspnea		
3. Fatigue/ tired/ listless/lack of energy/ washed out/ low energy/ weak/ other ways to describe?		
4. Other:		

- a. What are the 3 symptoms that have the greatest impact on your daily life?
- b. How would you describe [symptom] to someone who does not have [lung condition]?
- c. Does the experience of [symptom] impact any of your daily activities? If yes, how?
- d. How often do you have [symptom]?
 - *Probe*: Ask about different timeframes – in a day and in a week.
- e. Does the severity of [symptom] change day to day?
 - *Probe*: How would you describe your 'usual' severity of [symptom]?
 - *Probe*: How do you know when [symptom] is getting worse or getting better?
- f. When do you have [symptom]?
 - *Probe*: Do you have [symptom] during the day? At night?
 - *Probe*: Are there times when you are more likely to have [symptom]?
 - *Probe*: What triggers your cough? Do certain things trigger the cough more than others?
- g. When did you first experience [symptom]? Has this symptom changed in any way since you first started experiencing it? If yes, tell me more about how it has changed.

Symptom	a. Description	b. Impact	c. Frequency	d. Usual Severity	e. Timing (i.e. Day? Night?)	f. Start and Change Over Time
Cough						
Shortness of Breath/Dyspnea						
Fatigue/ tired/ listless/lack of energy/ washed out/ low energy/ weak/ other ways to describe?						
Other						

4. How does having [lung condition] affect your day to day life right now? [If the following areas are not mentioned spontaneously, please probe]
- a. Activities of daily living (e.g., taking care of household)
 - b. Physical Impacts
 - c. Sleep
 - d. Emotional Impacts
 - e. Social Impacts (e.g., interactions with friends)

5. Is this different from how it affected your life when you were first diagnosed?

COGNITIVE INTERVIEW: DISCUSSION OF THE L-PF (UP TO 20 MIN)

Now, we will ask your input on another specific set of two questionnaires. Please take as much time as you need to complete this questionnaire as you normally would, say in a doctor's office.

[If the interview is being conducted over the phone, instruct the participant to say when they are done with the questionnaire so that time can be recorded.]

Time to complete Symptoms: _____

Time to complete Impacts: _____

1. What is your overall impression of these questionnaires?
2. What time period were you thinking about when you answered the questions?

ITEM LEVEL QUESTIONS: Symptoms

Let's go through each of the questions. Let's look at items 1–12

ITEMS 1–12: Short of Breath

1. Can you tell me in your own words what these items are asking about?
2. Are there days you avoid certain activities and days you do not?
3. Can you tell me 0 (not at all); 1; 2; 3; 4 means to you in this context? Can you tell me what marking No means to you in this context? What about "not applicable" (No-b)?
4. Were there any activities listed that stood out to you as not relevant to you? Were there any activities you felt should be included that aren't listed?
5. Is there anything else you would like to add or mention about these items?

ITEMS 13–18: Cough

1. Can you tell me in your own words what these items are asking about?
2. Do you experience coughing every day?
3. What does the phrase "annoying tickle in your throat" make you think of?

4. Can you tell me 0 (not at all); 1; 2; 3; 4 (constantly) means to you in this context?
5. Is there anything else you would like to add or mention about these items?

ITEMS 19–23: Fatigue/Energy

1. Can you tell me in your own words what these items are asking about?
2. Do you experience fatigue daily?
 - a. **If yes, then ask:** If you were describing “fatigue” from [lung condition] to a friend, what would you say?
3. Does coughing impact your energy levels? What about shortness of breath?
4. Can you tell me 0 (extremely low); 1; 2; 3; 4 (excellent) means to you in this context? How about 0 (nothing) – 4 (everything); 0 (no energy) – 4 (a lot); 0 (no effect at all) – 4 (a lot); 0 (no time at all) – 4 (an extremely long time)?
5. Is there anything else you would like to add or mention about these items?

ITEM LEVEL QUESTIONS: Impacts

Let’s go through each of the questions. Let’s look at items 1–16

ITEMS 1–16: Impacts

1. Can you tell me in your own words what these items are asking about?
2. What does the phrase “exerted physically” mean to you?
3. Are there times when you feel embarrassed about your coughing? What about the coughing is embarrassing?
4. What does “pulmonary fibrosis” mean to you?
5. Can you tell me 0 (not at all); 1; 2; 3; 4 (extremely) means to you in this context? How about 0 (extremely poor) – 4 (excellent)?
6. Is there anything else you would like to add or mention about these items?

ITEMS 17–19: Symptoms on QoL

1. Can you tell me in your own words what these items are asking about?
2. What does quality of life mean to you? What were you thinking about when you answered these items?
3. Can you tell me 0 (made my QoL extremely poor); 1; 2; 3; 4 (no negative effect) means to you in this context?
4. Is there anything else you would like to add or mention about these items?

ITEMS 20–21: Physical Health and QoL

1. Can you tell me in your own words what these items are asking about?
2. What does physical health mean to you? Do you think of all aspects of health or just health related to [lung condition]?
3. Did you have any difficulty understanding these items?
4. Can you tell me 0 (extremely poor); 1; 2; 3; 4 (excellent) means to you in this context?
5. Is there anything else you would like to add or mention about these items?

CONCLUSION OF DISCUSSION ABOUT ILD (UP TO 5 MIN)

1. Do you have any other thoughts about your personal experience that I have not asked about that you would like to share with me?
2. If you were sitting next to someone who was just diagnosed with [lung condition], what would you tell them?