## Appendix 1

## A List of Interview Questions for Lung Cancer Patient: Qualitative Interview Guide

### General

- Which symptoms of lung cancer have the greatest impact on a person's quality-of-life or disease burden?
- How is an individual with lung cancer's life altered by having lung cancer?
- What changes would greatly improve your overall satisfaction with life?

### Physical

- Could you give examples of how a person with lung cancer is affected physically by the disease?
- Has fatigue interfered with your life?
- Do you have problems breathing? If so, how does this affect you?
- Does a cough trouble you? How does this affect your life?
- Do you have any problems with your sleep or with daytime sleepiness?
- Has weakness interfered with your life?
- Has lung cancer interfered with your appetite?
- Have nausea or problems eating interfered with your life?
- Have you noticed any change in your voice? How has this affected you?
- Has lung cancer changed how you view yourself or your perceived body image?
- Do you experience pain? Where do you experience this? How does it affect your life?
- What types of functional limitations are most important to a patient with lung cancer?
- Are there specific activities that you have difficulty doing?

### Mental

- Do you have difficulty concentrating, reading, remembering, or thinking? How has this affected you?

# Emotional

- Could you give examples of how a person with lung cancer is affected emotionally by the disease? For instance, do you feel that fear, anxiety, moodiness, or depression have an impact on your life?

#### Social

- How does lung cancer affect the social health of a person (e.g. relationship with family, work colleagues, or friends)?
- In what ways does lung cancer affect family life?
- Has lung cancer interfered with how you interact with others?
- What activities with your friends do you have difficulty participating in?

#### Everyday

- What is the most troubling problem a person with lung cancer has to face?
- What are the "little things" that are affected by and important to people with lung cancer?
- What are the most important questions a healthcare provider should ask someone with lung cancer?
- What are the ways that lung cancer affects someone's everyday life?
- How does lung cancer interfere with your job or your ability to get a job?
- What type of activities around the house do you have difficulty with?
- What ways is a patient's independence affected by lung cancer?
- What areas of your life would you most like to improve?
- Are there side effects from lung cancer treatment that have affected your life? What are these?
- If a successful therapy was developed, what would it do for you?
- Are there other areas that have a major impact on your quality-of-life or disease burden that we did not mention and that have not been brought up?

Table S1 Supplemental	data on symptoms from	cross-sectional study
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Table S1 Supplemental data on symptoms from cross-sectional study           Symptomatic themes (italicized) & individual symptoms	Prevalence (%)	Average impact (0-4)	PIP (0-4)
Fatigue	85.5	1.60	1.37
Social role dissatisfaction	45.5	1.67	0.76
Breathing difficulties	66.4	1.34	0.89
Impaired body image	54.5	1.30	0.71
Impaired sleep and daytime sleepiness	73.5	1.43	1.05
Difficulty thinking	62.5	1.28	0.80
Limitations with your physical function	72.8	1.54	1.12
Gastrointestinal issues	59.3	1.38	0.82
Social role limitations	43.7	1.27	0.55
Emotional issues	73.0	1.54	1.12
Pain	50.7	1.16	0.59
Inability to do activities	61.6	1.64	1.01
Communication difficulties	27.4	1.00	0.27
Choking or swallowing issues	28.7	0.79	0.23
Tiredness	87.6	1.45	1.27
General fatigue	81.0	1.61	1.30
General weakness	61.8	1.44	0.89
Fatigue after physical activity The need for prolonged recovery time	80.9	1.57	1.27
	64.2	1.45	0.93
Exhaustion	56.2	1.53	0.86
Decreased stamina	82.5	1.63	1.34
Inability to do things previously done	78.5	1.76	1.38
Social isolation	59.6	1.75	1.04
Impaired interaction with family members	41.9	1.56	0.65
Exhaustion from social interactions	48.5	1.23	0.60
Dissatisfied with social interactions	42.2	1.46	0.62
Impaired interactions with friends	40.4	1.36	0.55
Not as excited to participate in social activities	49.3	1.55	0.76
Coughing	48.5	1.02	0.49
Shortness of breath	64.2	1.39	0.89
Breathing problems	53.3	1.29	0.69
Having a weak cough	31.6	1.14	0.36
Chest pain	27.0	1.08	0.29
Having to cough up phlegm	32.8	0.64	0.21
Difficulty breathing during strenuous activities	70.9	1.77	1.25
Throat problems	24.8	1.29	0.32
Having to clear your throat	47.8	0.98	0.47
Having to cough up fluids	22.1	0.80	0.18
Exhaustion with coughing	19.0	0.69	0.13
Cough interfering with activities	20.6	0.96	0.20
Shortness of breath with activity	69.3	1.56	1.08
Dizziness	37.0	0.82	0.30
Bloody cough	2.2	0.33	0.01
Lightheadedness	41.6	0.67	0.28
Weight gain	54.0	1.61	0.87
Hair loss	40.1	1.24	0.50
Negative thoughts about your body image	60.3	1.48	0.89
Tired appearance	68.1	1.24	0.84
Weight loss	25.0	0.88	0.22
Feeling different from other people	61.8	1.39	0.86
Daytime sleepiness	72.6	1.14	0.83
Excessive sleep requirements	51.5	1.28	0.66
The need for naps	63.0	1.05	0.66
Insomnia	61.5	1.30	0.80
Cough preventing sleep	13.3	0.94	0.13
Pain preventing sleep	25.2	1.41	0.36
Difficulty sleeping	60.7	1.44	0.87
Decreased motivation	67.4	1.60	1.08
Problems concentrating Memory problems	65.2 68.7	1.39	0.91 0.87
Difficulty reading	35.6	1.38	0.49
Difficulty recalling words	64.4	1.40	0.90
Difficulty with comprehension	34.8	1.36	0.47
	72.6	1.66	1.21
Impaired physical activity Impaired walking	47.0	1.54	0.72
Difficulty walking long distances	61.5	1.80	1.11
The need to pace oneself when doing activities	79.3	1.50	1.19
Difficulty going up or down stairs	61.9	1.70	1.05
Leg weakness	45.1	1.68	0.76
Difficulty running	76.3	2.04	1.56
Falls	21.5	1.21	0.26
Difficulty standing	26.1	1.60	0.42
Difficulty keeping pace with friends	53.7	1.31	0.70
Trouble going up hills	70.1	1.71	1.20
Having to grab on to things when walking	36.1	1.42	0.51
Difficulty getting up from laying down	33.1	1.16	0.38
Limitations with your mobility or walking	40.3	1.44	0.58
Problems with your hands or fingers	41.8	1.39	0.58
Arm weakness	40.0	1.15	0.46
Decreased ability to carry a heavy load with your arms	57.0	1.39	0.79
Shaky hands	25.2	1.24	0.31
Problems with your shoulders or arms	41.0	1.55	0.64
Impaired sexual function	44.4	1.93	0.86
Nausea	25.6	0.97	0.25
Decreased appetite	29.0	0.79	0.23
A change in the taste for food	36.6	0.90	0.33
Blandness of food/lack of flavor	26.1	0.69	0.18
Difficulty eating	17.4	0.87	0.15
Incontinence	19.4	1.42	0.28
Constipation	40.2	0.94	0.38
Increased bathroom urgency	45.1	1.53	0.69
Decreased sense of smell	11.2	0.47	0.05
Abdominal pain	26.3	0.86	0.23
Diarrhea	46.6	1.18	0.55
Decreased independence	39.8	1.47	0.59
Reliance on family members	45.1	1.53	0.69
Reliance on others	41.2	1.43	0.59
The need for increased planning prior to social interactions	45.5	1.32	0.60
Difficulty being heard in a social setting	23.5	1.35	0.32
Avoidance of social activities	41.4	1.35	0.56
Having to cancel plans due to tiredness	37.1	1.02	0.38
Decreased participation in family activities	32.3	1.49	0.48
Difficulty helping with family chores	43.2	1.40	0.60
Difficulty holding children	16.7	1.59	0.27
Limited ability to participate in fun activities	49.6	1.35	0.67
Fear of worsening of the disease	91.7	1.86	1.71
Anxiety	79.5	1.82	1.45
Depression	63.6	1.76	1.12
Preoccupation with thoughts about the disease	80.0	1.38	1.10
	68.2	1.51	1.03
Emotional strain	68.9	1.64	1.13
Feeling like a burden to others	57.6	1.45	0.84
Aggravation	58.5	1.28	0.75
Afraid to go places due to fear of feeling sick	30.0	1.23	0.37
Moodiness	50.0	1.42	0.71
Self-pity	42.3	1.09	0.46
Anger	49.2	1.11	0.55
Reduced ambition	56.1	1.45	0.81
Feeling vulnerable	62.9	1.34	0.84
Damaged pride with loss of independence	37.9	1.48	0.56
Frustration	62.9	1.41	0.89
Grief	52.7	1.46	0.77
Agitation	48.1	1.13	0.54
Back pain	53.5	1.49	0.80
Headaches	43.4	1.07	0.46
Shoulder pain	41.5	1.74	0.72
Throat pain	16.9	1.18	0.20
Rib pain	33.3	1.26	0.42
Pain when talking	8.5	0.73	0.06
Pain from coughing	12.3	0.81	0.10
Pain with movement	31.3	1.29	0.40
Lung pain	23.7	1.16	0.27
Neck pain	33.1	1.52	0.50
Difficulty breathing due to pain	10.7	1.21	0.13
Muscle soreness	42.0	1.33	0.56
Arm pain	26.0	1.32	0.34
Sore mouth	19.5	0.84	0.16
Numbness	32.3	1.38	0.45
A tingling sensation at your feet or hands	45.8	1.13	0.52
Difficulty cleaning your house	65.9	1.52	1.00
Impaired ability to exercise	77.3	1.59	1.23
Difficulty maintaining your personal hygiene	20.2	1.31	0.26
Difficulty washing dishes	23.7	1.13	0.27
Problems standing in the shower	20.0	1.04	0.21
Nausea after activities	13.8	0.67	0.09
Difficulty playing sports	56.9	1.59	0.90
Difficulty doing laundry	26.7	1.14	0.30
Difficulty taking care of the lawn	34.1	1.75	0.60
Difficulty feeding yourself	3.8	1.20	0.05
Difficulty dressing yourself	13.8	0.56	0.08
Difficulty preparing food	19.1	0.88	0.17
Strained voice	24.6	1.47	0.36
Hoarse voice	28.7	1.22	0.35
Difficulty speaking	14.7	0.79	0.12
The need to repeat yourself often when speaking	19.4	1.20	0.23
Raspy voice	21.7	1.21	0.26
Soft voice	24.0	0.77	0.18
Problems hearing	34.6	1.24	0.43

Problems hearing	34.6	1.24	0.43
Problems seeing	26.9	0.97	0.26
Heartburn	50.0	1.32	0.66
Problems swallowing	22.3	1.34	0.30
Choking	16.2	0.95	0.15

Prevalence, average impact, and population impact (PIP) of symptomatic themes (italicized) and individual symptoms inquired about in Lung Cancer (LC) cross-sectional study. n=139.

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