

Interview Guide for COPD Patients’ Perspectives on Pulmonary Rehabilitation

This script is intended as a guide. In order to develop rapport, the interviewer will seek to set a conversational tone, diverging at some points from the script. They will use discretion in phrasing and in using probes and additional questions to fully understand the interviewee’s perspective and to take into account prior responses.

All interviews will be audio-recorded and transcribed upon completion. Be sure to ask patients if they’re comfortable in the space, or if they would need to be elsewhere to feel comfortable completing the interview. As appropriate, remind participants they do not have to answer questions if they’re not comfortable responding.

Be sure to start the conversation by identifying yourself as not being a member of the medical team or the pulmonary rehab team.

While the abbreviation PR is used throughout this guide, please read it to the participant as ‘pulmonary rehab.’

INTRODUCTION (to be covered as part of recruitment and informed consent process)

- [Script:]
- “You are being invited to participate in this research study because you were admitted to the hospital for a flare-up or exacerbation of chronic obstructive pulmonary disease or COPD.
- We are interested in your thoughts about a program called pulmonary rehabilitation designed for individuals with COPD to help them breathe easier and have more strength and energy.
 - We are especially interested in your perspectives on what things might stand in the way of you participating in pulmonary rehabilitation after you leave the hospital and what things might help overcome those barriers.
- Our goal today is not to provide a comprehensive overview of pulmonary rehab or to enroll you in pulmonary rehab; we are only looking for your thoughts and suggestions on how we can increase the number of patients who participate in this important program.
- This interview should take approximately 40-60 minutes. To thank you for your time, you will be offered a \$50 gift card at the end of this interview.
- Just to remind you, this interview will be audio-recorded. By continuing forward, you’re agreeing to participate in this study. Before we start, do you have any questions for me?”

[Answer any questions, and then start audio recording]

QUALITATIVE QUESTIONS:

1. Could you tell me about your experience having COPD?
 - a. How long have you had COPD?
 - b. Could you tell me about your experiences being hospitalized for COPD?
 - c. In what ways has COPD affected your life?
 - i. Probe: Has COPD prevented you from being able to do things you used to enjoy doing? For example: work, spend time with your family, and engage in activities.
 - d. Have your medicines helped you to breathe and feel better?
2. Are you familiar with the idea of Pulmonary Rehabilitation?

Supplement: Spitzer et al. “You leave there feeling part of something”: A qualitative study of hospitalized COPD patients’ perceptions of pulmonary rehabilitation

- a. If yes:
 - i. How would you describe Pulmonary Rehabilitation to someone else?
3. Have you ever participated in a PR program before?
 - a. If yes:
 - i. What was your experience like?
 - ii. How many sessions did you complete?
 - iii. What did you like most about rehabilitation?
 - iv. What did you like least about rehabilitation? [*go to #7*]
 - b. If no:
 - i. Has it ever been recommended to you?
 1. If yes:
 - a. What impacted your decision to not attend? [*go to #4*]
 2. If no: [*go to #4*]
4. Do you know anyone who participated in pulmonary or cardiac rehabilitation?
 - a. If yes:
 - i. What did they say about it? [*go to PR description /#6*]
 - b. If no: [*go to #5*]
5. Have you ever participated in any form of rehabilitation, for example, like after a hospitalization or a surgical procedure like joint replacement?
 - i. [If yes: *draw attention to similarities between it and PR*]

[*Script:*] Just to make sure we’re on the same page, here is some information about Pulmonary Rehab:

Pulmonary rehab is a program that provides exercise training, education about COPD, tips on how to complete everyday activities without becoming so short of breath, and advice on how to live better with your disease. Many different types of medical professionals would work with you in the program. These include doctors, nurses, respiratory therapists, exercise specialists, and dietitians. You would work with this team to create a special program for you.

A few other things you should know about pulmonary rehab:

Patients who attend pulmonary rehab typically go 2-3 times a week for 8-12 weeks, and sessions generally last 2 hours. There is typically a copay each time you go to PR, which varies depending on insurance. Research studies have shown that patients who participate in pulmonary rehab develop better strength and stamina, and have a reduction in symptoms. For example, they can walk further, climb more stairs, and do more household activities than before pulmonary rehab. Patients who complete the program and join a maintenance program have benefits that last for two years or more. That’s the good news. The bad news is that only a small percent of people with COPD who would benefit end up attending PR; this is where we need your thoughts and ideas.

6. Based on what we’ve talked about so far, do you think PR is something that might be beneficial for you?
 - a. If yes: What are ways in which PR might be helpful for you?

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- b. If no: Why do you think PR would not be beneficial for you?
7. Although many patients with COPD could benefit from participating, only a small number of people complete the program. What are the kinds of things that might keep you from attending PR? [*if people said they attended PR before, reframe this question as about experience – i.e. what made it difficult for you to attend? What might keep other people from attending?*]
 - a. If they get stuck on this question, offer examples: “*Some things other people have mentioned are not feeling well enough, cost/copays, transportation, family responsibilities, work, or being a current smoker*”
8. We’ve been talking about barriers. We’d like to talk about ways to encourage and make it easier for patients to attend PR. Can you think of ways we could encourage and make it easier for patients with COPD, like you, to participate in PR?
 - a. Meet PR staff while you’re in hospital?
 - b. Watch a video introducing you to the facility and staff, and see others participate in PR?
 - c. Be introduced to another person with COPD who has successfully completed PR to learn about their experiences and receive support and encouragement?
 - i. What are the best ways you’d want to stay in touch with them?
9. What are some other questions you might have about PR?
10. How important is a physician’s recommendation to you in your decision about starting PR?
 - a. What about other kinds of health professionals?
11. From everything we’ve talked about so far, what are the most important benefits we should be telling patients about PR?
12. Is there anything we haven’t asked about that you would like to tell us?

[Adjust to match participant’s tone] Thank you so much for your time. It’s been wonderful getting to hear your thoughts about PR today. We hope you have a great day/your day improves and wish you a speedy recovery.

[Offer brochure on PR for COPD from ATS]

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The following questionnaire was administered by the interviewer and collected via REDCap.

Gender

- Woman
- Man
- Other

Race (Select all that apply)

- American Indian or Alaskan Native
- Asian
- Black or African-American
- Native Hawaiian or Other Pacific Islander
- White

Ethnicity

- Hispanic/Latino
- Not Hispanic/Latino

Educational Attainment

- Did not complete high school
- High school degree
- Some college
- Associate's degree
- Bachelor's degree
- Master's degree or higher

How long have you had COPD or When was the first time you were told you had COPD?

- During this hospitalization
- Within the past year
- More than 1 year ago but less than 5 years ago
- More than 5 years ago

Smoking status

- Never smoked
- Smoked in the past but no longer (quit >30 days ago)
- Smoked in the past 30 days

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The following scales were handed to the participant and scores were entered into REDcap.

mMRC Breathlessness Scale	
<i>Before you got sick and needed to go to the hospital, how breathless were you?</i>	
Grade	Description of Breathlessness
0	I only get breathless with strenuous exercise
1	I get short of breath when hurrying on level ground or walking up a slight hill
2	On level ground, I walk slower than people of the same age because of breathlessness, or have to stop for breath when walking at my own pace
3	I stop for breath after walking about 100 yards or after a few minutes on level ground
4	I am too breathless to leave the house or I am breathless when dressing

COPD assessment test (CAT)							
<i>Before you got sick and needed to go to the hospital, how was your COPD?</i>							
When I walk up a hill or one flight of stairs I am not breathless	0	1	2	3	4	5	When I walk up a hill or one flight of stairs I am very breathless
I never cough	0	1	2	3	4	5	I cough all the time
I have no phlegm (mucus) in my chest at all	0	1	2	3	4	5	My chest is completely full of phlegm (mucus)
My chest does not feel tight at all	0	1	2	3	4	5	My chest feels very tight
I am not limited doing any activities at home	0	1	2	3	4	5	I am very limited doing activities at home
I am confident leaving my home despite my condition	0	1	2	3	4	5	I am not at all confident leaving my home because of my lung condition
I sleep soundly	0	1	2	3	4	5	I don’t sleep soundly because of my lung condition
I have lots of energy	0	1	2	3	4	5	I have no energy at all