

ATTACHMENT 10:
IN-DEPTH INTERVIEW GUIDE

Study Title: “People Living with Lung Cancer”

IN-DEPTH INTERVIEW GUIDE

I. Goal:

The purpose of the *Research with People Living with Lung Cancer* study is to understand key experiences of individuals with lung cancer across three general domains: 1) the diagnosis process, 2) stigma and victim blaming, and 3) provision of counseling and support services. In addition, we will examine these domains among three audience segments: *smokers, former smokers, and those who never smoked*. By improving our understanding in these areas, we can identify future research needs and inform the development of information and services for individuals affected by lung cancer.

II. Approach:

This research is exploratory. As such, we will use a *general interview approach*, as advocated by Patton (1990). This approach involves outlining a set of topics to be discussed in the interview. These topics then serve as a checklist for what needs to be covered in the interview, with the actual order of discussion items guided by the context of the interview. Importantly, the interviewer is free to follow a more conversational style in the interview.

Interviewer Note:

One’s smoking history and its relationship to the diagnosis and overall experience of lung cancer is one of our interests in interviewing individuals who have previously smoked and developed lung cancer. Nonetheless, the sensitive nature of this topic suggests a need to explore this issue at each individual’s own comfort level. If individuals bring this up in the course of an interview, we will explore and probe on their comments to understand better this dynamic, taking care to be sensitive to their level of comfort on this issue. Domain 2 provides possible questions to ask regarding smoking. However, if an individual avoids or is uncomfortable with this topic, we will not pursue smoking issues further in the interview.

Public reporting burden of this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-XXXX).

III. Question Guide

Introduction

Thank you for participating in this interview today. Your participation is very important. I'm _____ from RTI International. I am conducting these interviews for the Centers for Disease Control and Prevention (CDC). The purpose of this interview is to learn more about people living with lung cancer and how health care providers, doctors, nurses, educators, and others can help. Your thoughts and suggestions are very important to us, and we appreciate your taking the time to talk with us. The interview should take no more than 1 hour total.

- Your name and anything you say here will be handled in a private manner. We do not plan to share your name, address, or phone number with anyone other than members of the research team, and no one will contact you about this interview. When I write my report, I will not refer to you by name.
- There are no right or wrong answers. We want to know about your feelings, thoughts, and experiences. You are the expert here.

Consent

Before we begin, please let me know if at any time you need to stop or take a break. We do not have to complete this interview today and can arrange to call you back if that's more comfortable for you.

I now want to go over the consent statement that we mailed to you. I am going to read it to you and then ask if you have any questions.

Questions

1. Please tell me how you came to be diagnosed as having lung cancer?

Potential Probes:

What brought you to the doctor?

Probe: Was that your regular doctor?

Were you experiencing any symptoms?

What do you think might have been causing these symptoms?

Former/Never Smokers:

Since you quit smoking/never smoked, did you or your doctor suspect lung cancer?

How long did it take after you first went to the first doctor to find out you have lung cancer?

Can you describe all you went through before learning of your diagnosis?

What tests did you get as part of diagnosing your cancer?

Were you referred to a specialist? More than one?

At what point was the possibility of lung cancer brought up? What was your reaction? When was your diagnosis confirmed?

Looking back, is there anything you wish had been done differently?

What concerns or issues did you have when you were going through this experience? Were they addressed? Did you get help for _____?

Your questions answered?

Former Smokers:

I have noted here that you used to smoke, but don't any more. When did you quit? What led up to your decision to quit smoking?

Potential Probes:

Since you quit ___ years ago, what was your reaction to learning you had lung cancer?

2. Once you learned you had lung cancer, what happened next?

Potential Probes:

How did you decide what to do in terms of treatment or care?
Looking back on your experience with having lung cancer diagnosed and then going through treatment, was there anything you would have done differently?

3. Was anyone with you to help you through the process?

Potential Probes:

Did anyone help you understand what happens next with treatment and care?

4. In thinking about all you have gone through with your lung cancer, what were some of the challenges?

Potential Probes:

What positive things did your doctor do? Was there anything that you wished your doctor had done differently?
Where you satisfied with the process? What process—the whole thing or some specific part? Why or why not?
What was hardest about the process? What was the most difficult thing that you had to deal with? What advice would you have for others who might get a diagnosis of lung cancer?

5. Next I'd like to discuss how different people have reacted when they learn that you have lung cancer. What's been the reaction of your family and friends? What about others around you? Coworkers?

Potential Probes:

What have been some of the other ways people have responded?
Do you get different responses from different kinds of people? How so?
Do people say anything to you? Are there people who say nothing?

6. Some people have said they have felt blamed for getting lung cancer. Have you ever felt this way? How so?

Potential Probes:

What have people said or done? What was your reaction? How did you feel, what did you say?
Who has been your biggest support system? Family? Friends? Health care providers?
Who or where have you encountered the most difficulty?
What about your health care providers?
You mentioned that you used to smoke, does that come up in the conversation or reactions? How?

Former Smokers:

You mentioned that you used to smoke, does that come up in the conversation or reactions? How?

Never Smokers:

Have you ever found people assumed you must have smoked?

7. What has been most difficult about living with lung cancer?

Potential Probes

What are some other issues you have had to deal with?

Nonsmokers:

As a nonsmoker who has been diagnosed with lung cancer, what would you most like to share with others about the experience?

8. In dealing with these difficulties (or problems), what kind of strategies have you found to deal with them?

Potential Probes:

Services

Who has helped you through this?

What, if any, organizations have you found to help you with these needs?

What support or services have you found?

How often do you use these services?

Have you found support specifically for people living with lung cancer?

How useful have you found the services to be? How could they be improved?

Counseling

Have you used any kind of counseling or support services?

What was your experience with those services?

Did you find these services useful? How could they be improved?

9. Are there other services or supports that you would like to see made available for individuals diagnosed with lung cancer?

Closing

10. Is there anything that you think we should know that we haven't discussed?

11. What is the one thing that you would want to share with others who are diagnosed with lung cancer?

Remind participants of information for cancer-related services and support located on the back of the Informed Consent.