PATIENT PERCEPTIONS OF BIOMARKER TESTING

A mixed-methods approach to understand the patient experience related to biomarker testing for NSCLC

APPENDIX B: Focus Group Guide

1. Introductions and Orientation to Online Meeting (5 MINS)

- a. Explanation of research
- b. Assurance of neutrality
- c. Orientation to online meeting platform
- d. Discussion rules
- e. Confidentiality/Observation/Recording

2. Participants Self-Introduce (5 MINS)

- a. Name
- b. Where located
- c. Family/Work/Free time
- d. Type of Lung cancer
- e. How long
- f. Current status of cancer/treatment/recovery/living with

3. Testing and Target Therapy Awareness/Knowledge (10 MINS)

- a. In our discussion today we are going to talk about a particular type of test associated with lung cancer and what that test can mean for treatment decisions.
- b. SHOW WORD WITH OPEN-END RESPONSE BOX: "Biomarker Testing" What do you know, or have you heard about "biomarker testing"? Type your responses in the window. If you have not heard this term, just answer what it sounds like to you? What comes to mind when you hear it?

DISCUSS:

- c. How would you describe biomarker testing to someone who knows nothing about it?
- d. What does biomarker testing help you understand about your cancer?
- e. What do you know about how it informs your treatment options?
- f. For those who are familiar, think back...
 - i. When in your cancer experience did you first hear about biomarker testing?
 - ii. Who or where did you hear about it?
 - iii. Can you recollect how you felt about learning this information?
- g. Who has had this type of testing? [GET SHOW OF HANDS] We will talk more about that in a bit.
- h. Who isn't sure if they've had this type of testing?

4. Biomarker Testing as a Path to Treatment (10 MINS)

- a. To get us all on the same page, I want to share some information about biomarker testing.
- b. Was there new information for people? What was new?
- c. FOR THOSE MORE FAMILIAR: Did this align with your understanding?
- d. Thinking about this information what do you think it could mean for you?
- e. What questions do you have? [LIST ON VIRTUAL WHITE BOARD]

5. Pathway to Testing (10-15 MINS)

- a. How would you expect to hear about this testing? Think about your experience with diagnosis and decisions around the first line treatment:
 - i. Who would you expect to talk to you about biomarker testing?
 - ii. When would you think it would come up in the process of diagnosis and treatment decisions?
- b. Who had their doctor proactively talk to them about biomarker testing?
- c. Who raised with their doctor first?
- d. Did you see a nurse or work with a nurse in your oncologist's office at any time to discuss biomarker testing? What was that experience like?

- e. For those who did **not** get informed about biomarker testing during the initial diagnosis and treatment stage, what do you think should /wish would have happened?
- f. Did anyone have the experience of being told biomarker testing was not appropriate or could wait? How was that explained to you?
 - i. Did you get a second opinion?
 - ii. What do you think might have empowered you to do so?
- g. What would be reasons why your doctor might not raise biomarker testing with you?
 - i. How does this make you feel?
 - ii. How would you want to change that? What would help you?

6. Testing Experience (10-15 MINS)

- a. What are some of your questions about getting tested? [OPEN-END THEN PROBE IN KEY AREAS:]
 - i. Procedure, what's involved
 - ii. Results, how long will it take to know results
 - iii. How will the doctor use the results of the test
 - iv. Costs of testing
 - v. Insurance coverage
 - vi. Cost of therapy
 - vii. Moving forward with other treatment while waiting for test or results
- b. [FOR THOSE WHO HAVE HAD TESTING:] I want to learn about your experience with testing. How smooth or difficult was the process?
 - i. From learning that you had lung cancer to learning the results of your biomarker testing results, how long did that take?
 - ii. What kind of decisions did you make about your care while you were waiting for your testing results?
 - iii. Did you know the costs/your obligations before getting tested?
 - iv. How did knowing that impact your decision? If you didn't know the cost, would that have impacted your decisions?
 - v. How did insurance and the labs, testing companies handle the cost?
 - vi. Did you encounter any resistance? How did you deal with that?
 - vii. Would a financial assistance program or a maximum Out of Pocket (OOP) limit have made a difference for you (or was that not really an issue)?

7. Understanding Biomarker Test Results (5-10 MINS)

- a. [FOR THOSE TESTED] How were your test results shared with you?
 - i. At what level of detail? [PROBE: High level had a biomarker or not vs. shared the lab report and walked through it, etc.]
- b. How well did you feel you understood what they meant? How they informed your treatment?
- c. How important is it to you to understand the results of your testing? Versus, the care team understands them and recommends the course of action?
- d. [IF TESTED AND DON'T KNOW RESULTS] Have you wanted to find out your results? How did you approach that?
 - i. What was a barrier to your finding out?
 - ii. What would you have done with this information?

8. Improving Biomarker Testing Access and Process (15 MINS)

- a. For the remainder of our discussion, we are going to work as a group on how to improve the access and process of biomarker testing for lung cancer. We've heard that access to testing is an issue, and we want to know how we can help. Let's brainstorm some ideas for how we can better support lung cancer patients getting access to biomarker testing.
 - i. What is the best way for you to learn about this testing?
 - ii. Who do you want to talk to about it? Who do you want to be able to ask questions of?
 - iii. When feels like the right time?
 - iv. What are the key pieces of information that should be presented to you when you are first being told about testing?

- b. What do you need to understand about costs and insurance?
 - i. What services such as a financial navigator would be helpful?
 - ii. What about direct help from the testing company?
 - iii. What should the maximum OOP cost be to bring testing within reach?
- c. How should testing and results be communicated?
 - i. When?
 - ii. Where
 - iii. Format?
 - iv. Which providers or providers should do this? Do you see a role for a biomarker testing counselor?
- d. [SHARE LUNGevity COLLATERAL] Let's look some pieces that LUNGevity has prepared and get your feedback?
 - i. SHOW 4R PLANNING TOOL:
 - ii. What is helpful?
 - iii. Clear/unclear?
 - iv. Would this have helped you when you were deciding on tests and treatment?
 - v. What could make this better?
- e. What other ideas do you have?

9. Wrap and Close

- a. ASK ANY FOLLOW-UP QUESTIONS
- b. Thank and dismiss group