PATIENT PERCEPTIONS OF BIOMARKER TESTING
A mixed-methods approach to understand the patient experience related to biomarker testing for NSCLC

APPENDIX A: Patient Survey

1. To confirm, are you a
   1. A lung cancer patient/survivor
   2. Caregiver or former caregiver to a lung cancer patient     TERMINATE
   3. Neither                                                TERMINATE

2. What is your age? ________ [PROGRAM OPEN END RANGE 0-99, TERMINATE IF LESS THAN 21]

3. What is your current status with respect to treating your lung cancer?
   1. Have been diagnosed but not begun treatment
   2. Am undergoing treatment now (first-line treatment)
   3. Completed treatment/monitoring
   4. Completed treatment and no evidence of disease
   5. Have recurrence/undergoing additional treatment
   6. Other [Describe briefly: ______________________]

To understand the full range of experiences with lung cancer treatments, we want to ask you some questions about your background and access to healthcare. This information will be very helpful to analyze the results and help us understand and address the unmet needs of all lung cancer patients.

4. What do you consider yourself? Select all that apply.
   1. White/Caucasian
   2. Black/African American
   3. Asian, Pacific Islander
   4. American Indian
   5. Other
   6. Prefer not to answer

5. [SHOW ON SAME PAGE AS PREVIOUS] Are you from a Hispanic, Latino, or Spanish-speaking background?
   1. Yes
   2. No
   3. Prefer not to answer

The next questions are about health insurance. Include health insurance obtained through employment or purchased directly as well as government programs like Medicare and Medicaid that provide medical care or help pay medical bills.

6. Are you covered by any kind of health insurance or some other kind of health care plan?
   1. Yes
   2. No     GO TO Q12A

IF Q6=1 “YES”

7. What kinds of health insurance or health care coverage do you have? (Select all that apply.)
   1. Private health insurance
   2. Medicare
   3. Medigap (supplemental insurance for Medicare)
4 Medicaid (may also be called by your state’s program name such as Medi-Cal in California, etc.)
5 Children’s Health Insurance Program (CHIP)
6 Military related health care: TRICARE (CHAMPUS) / VA health care / CHAMPVA
7 Indian Health Service
8 State-sponsored health plan (under Affordable Care Act/Obamacare)
9 Other government program
10 No coverage of any type
11 Refused
12 Don’t Know

8. [IF MEDICARE ABOVE, Q7=2] What type of Medicare coverage do you have?
   1 Part A- hospital only
   2 Part B- medical only
   3 Both Part A and Part B
   4 Medicare Advantage Plan (Part A, Part B and provide prescription coverage)
   5 Refused
   6 Don’t Know

9. [IF MEDICARE PART B; REFUSED OR DK ABOVE; Q8=2,5,6] Are you under a Medicare managed care arrangement, such as an HMO, that is, a Health Maintenance Organization?
   1 Yes
   2 No
   3 Refused
   4 Don’t Know

10. [IF MEDICARE, Q7=2] Are you enrolled in Medicare Part D, also known as the Medicare Prescription Drug Plan?
    1 Yes
    2 No
    3 Refused
    4 Don’t Know

11. [ASK IF Q7=1-9] A health insurance premium is the amount you or a family member pay each month for health care coverage. Do you or a family member pay a premium for your health insurance, Medicaid or other health care plan?
    1 Yes
    2 No
    3 Refused
    4 Don’t Know

12. [ASK IF Q7=1-9] A deductible is the amount you have to pay for health care services BEFORE your health insurance or health coverage plan will start paying your medical bills. Does your Medicaid plan have an annual deductible?
    Note: A deductible is different from a co-pay.
    1 Yes
    2 No
    3 Refused
    4 Don’t Know

RESUME ASKING ALL
12a. What was your TOTAL HOUSEHOLD income FROM ALL SOURCES before taxes in 2019? This information is used to aid in our analysis on access to care. Use your best estimate.
    1 Less than $15,000
    2 $15,000 to $24,999
    3 $25,000 to $34,999
4 $35,000 to $49,999
5 $50,000 to $74,999
6 $75,000 to $99,999
7 $100,000 to $124,999
8 $125,000 to $149,999
9 $150,000 to $199,999
10 $200,000 or more
11 Prefer not to answer

LUNG CANCER EXPERIENCE

13. Where have you received treatment for your lung cancer? (Select all that apply.)
   1. At a comprehensive cancer center (a large cancer center that treats cancer patients, does research, has specialists or teams dedicated to treating lung cancer, and educates the public about cancer)
   2. At a community cancer center (a small cancer center that treats patients within a certain area or a location and whose oncologists treat multiple types of cancer)
   3. At a university hospital (a hospital that is attached to a university medical school)
   4. At a local hospital that treats all diseases including cancer
   5. Other (please describe) ___________________________________________________
   6. I do not know

14. In what year were you first diagnosed with lung cancer? [DROP DOWN BOX, TERMINATE IF BEFORE 1999]

15. With what type of lung cancer were you diagnosed? (Select one.)
   1. Non-small cell lung cancer (NSCLC): Adenocarcinoma
   2. Non-small cell lung cancer (NSCLC): Large cell
   5. Carcinoid or neuroendocrine tumor - TERMINATE
   6. Small cell lung cancer (SCLC) - TERMINATE
   7. Other (please specify) _____________________
   8. I do not know

16. Which of the following best describes the current condition? (Select one.)
   1. Stage I non-small cell lung cancer (NSCLC)
   2. Stage II non-small cell lung cancer (NSCLC)
   3. Stage III non-small cell lung cancer (NSCLC)
   4. Stage IV/advanced-stage/metastatic non-small cell lung cancer (NSCLC)
   5. No evidence of disease (sometimes called remission)
   6. I do not know

BIOMARKER TESTING

17. Tell us if you have heard these terms before:
   1. Yes
   2. No

[RANDOMIZE]
   a. Biomarker testing
   b. Genetic testing
   c. Mutation testing
   d. Genomic testing
   e. Molecular testing
f. Tumor profiling  
g. Targeted therapy  

18. [ASK IF YES TO ANY OF A, C, D, E, F ABOVE IN Q17] Biomarker testing is also known as mutation, genomic, molecular testing, or tumor profiling. For the remainder of the survey, we will refer to all these terms as “biomarker testing.” How familiar are you with biomarker testing?
1 Very familiar  
2 Somewhat familiar  
3 Neither familiar nor unfamiliar  
4 Somewhat unfamiliar  
5 Very unfamiliar  

19. [ASK IF YES TO ANY OF A, C, D, E, F ABOVE IN Q17] When did you FIRST become familiar with biomarker testing?
1 Before my lung cancer diagnosis  
2 When I was first diagnosed with lung cancer  
3 After diagnosis but before my first treatment was started  
4 During my first treatment  
5 After my treatment ended  
6 At recurrence (when my lung cancer came back)  
7 At progression (when my lung cancer started growing)  
8 Other (please specify: __________)  

20. [ASK IF YES TO ANY OF A, C, D, E, F ABOVE IN Q17] To the best of your recollection, how did you FIRST learn about biomarker testing? Select only one. [RANDOMIZE]  
1 Oncologist  
2 Pulmonologist  
3 Surgeon  
4 Nurse/nurse navigator  
5 Palliative care team  
6 Radiologist  
7 My regular doctor/primary care physician  
8 Patient education materials I was given  
9 Internet research (Google, website, etc.)  
10 My caregiver  
11 Another (lung) cancer patient  
12 Patient advocacy group  
13 [ANCHOR] Other (please specify: __________)  

RESUME ASKING ALL RESPONDENTS. SHOW EXPLANATION:  
Please read the information below and answer the questions.  

Biomarker testing is used to identify mutations within the cancer cell that might tell us why the tumor behaves the way it does—why it grows or spreads, for example. Sometimes, doctors may recommend a certain targeted therapy that attacks that mutation. Not all mutations have matched targeted therapies. Biomarker testing is also sometimes called mutation, genomic, molecular testing, or tumor profiling. It is commonly conducted for certain types of lung cancer. In biomarker testing the doctor removes a small piece of cancer tissue and sends it to a lab for testing. It can be done on tissue taken during the biopsy that was performed to make the diagnosis of lung cancer or another biopsy performed at a later date. In some cases, biomarker testing can be done with a patient’s blood sample.  

21. Have you ever spoken to a doctor or other member of your care team about biomarker testing or targeted therapy?
1 Yes, I asked a doctor/health care provider about it
2. Yes, a doctor/health care provider brought it up with me
3. No, a doctor/health care provider has never brought it up with me

[IF AWARE OF BIOMARKER TESTING Q17= YES TO ANY OF A, C, D, E, F AND NOT TALKED TO HCP Q21=3 ABOVE:]

22. You indicated you are aware of biomarker testing but have not spoken to your doctor or care team about it. What are the reasons you have not talked about it? Select all that apply.

[RANDOMIZE]
1. I am not sure what questions to ask
2. I rely on my caregiver to ask the relevant questions about my treatment
3. I assume my doctor would talk to me about it if it was right for me
4. I am responding well to the treatment I am receiving, there is no need
5. There never seems to be time to discuss it
6. I don’t trust how my health information will be used
7. I don’t think I can pay for it
8. My insurance won’t cover it
9. [ANCHOR] Other [please explain: ________________________________]

[IF Q21=1, 2 TALKED TO DOCTOR/HCP ABOUT TESTING, ASK:]

23. How much do you agree or disagree with each of the following statements about biomarker testing and targeted therapy?
1. Strongly agree
2. Somewhat agree
3. Neutral
4. Somewhat disagree
5. Strongly disagree

[RANDOMIZE]
a. I felt that I had to press my doctor and/or my care team to do the testing
b. My doctor/care team seemed unfamiliar with biomarker testing
c. My doctor/care team said I could wait to get that testing until after I went through treatment
d. I was told that biomarker testing was not necessary for my type of lung cancer
e. I was told that biomarker testing was not available for my type of lung cancer
f. I was told my insurance would not cover biomarker testing

RESUME ASKING ALL

24. As far as you know, has biomarker testing been done on your lung cancer?
1. Yes, and I was told I have a specific biomarker
2. Yes, and I do not have a specific biomarker
3. Yes, but I do not know the results of my testing
4. I have not been tested for a biomarker related to lung cancer GO TO Q48
5. I really do not know whether this testing was done for me or not GO TO Q48

25. [IF YES ABOVE, Q24=1,2] Do you know what type of biomarker testing you received?
1. Testing for multiple mutations at a single time (sometimes referred to as next generation sequencing)
2. Testing for the most common mutations
3. I don’t know
4. Other
26. [IF YES ABOVE, Q24=1,2] Do you know how biomarker testing was done for your lung cancer?
Biomarker testing can be done using tissue from a biopsy or blood or both.
1. Tissue from my **lung biopsy** was used for biomarker testing. I was tested only once
2. **Blood-based** biomarker testing (sometimes referred to as a liquid biopsy). I was tested only once
3. Tissue from my **lung biopsy** was used for biomarker testing. I **underwent testing more than once**.
4. **Blood-based** biomarker testing (sometimes referred to as a liquid biopsy). I **underwent testing more than once**.
5. Both tissue-based and blood-based biomarker testing
6. I don’t know

27. [ASK IF BIOMARKER TESTING DONE, CODES 1, 2, 3 IN Q24] How many doctors did you see before you found one who would perform biomarker testing?
1. Just one
2. Two
3. More than two

28. [ASK IF BIOMARKER TESTING DONE, CODES 1, 2, 3 IN Q24] When was your biomarker test(s) performed? (Mark all that apply)
1. As part of the testing done to get diagnosed
2. Before starting your first treatment
3. After starting/completing your first treatment
4. At recurrence (when your cancer came back)
5. At progression (when your cancer started growing)
6. Some other time [briefly describe: __________]
7. I don’t know

29. [ASK IF PART OF DIAGNOSTIC/BEFORE TREATMENT, CODES 1, 2 IN Q28] Did your doctor wait for your biomarker test results before starting you on your first treatment?
1. Yes
2. No
3. I do not know

30. [ASK IF BIOMARKER TESTING DONE, CODES 1, 2, 3 IN Q24] How long did it take you to get the results of your biomarker test after the biopsy?
1. Within 14 days
2. More than 14 days but within 1 month
3. More than 1 month
4. I never received the results
5. I do not know

31. [ASK IF BIOMARKER TESTING DONE, CODES 1, 2, 3 IN Q24] Did your doctor [or someone on your care team] inform you of the results of your biomarker test?
1. Yes
2. No
3. I do not know

32. [ASK IF BIOMARKER TESTING DONE, CODES 1, 2, 3 IN Q24 AND YES ABOVE, RESULTS SHARED, Q31=1] How were your results shared with you? Select all that apply.
1. Results were discussed with me at an appointment
2. I was given a printed copy (at appointment or mailed to me)
3. I received an electronic copy (via email, thumb drive, etc.)
4. I accessed through my patient portal/electronic medical records
5. Some other way [briefly describe: _______________________]
33. [ASK IF YES ABOVE, Q32= 1, 2, 3, 4] How well did you understand the results explained in the biomarker testing results report?
   1. Very well
   2. Somewhat
   3. Not very well
   4. Not at all
   5. I didn’t look at the report

34. [ASK IF BIOMARKER TESTING DONE, CODES 1, 2, 3 IN Q24] Is it important to you to have a copy of or have access to your biomarker testing results?
   1. Yes
   2. No
   3. I don’t know

35. [ASK IF BIOMARKERS IDENTIFIED, CODE 1 IN Q24] Which biomarker(s) was/were identified when you had biomarker testing? (Select all that apply.)
   1. ALK
   2. BRAF
   3. EGFR
   4. HER2
   5. KRAS
   6. MEK1
   7. MET
   8. PD-L1 (used to decide whether immunotherapy is the right treatment choice)
   9. PIK3CA
   10. RET
   11. ROS1
   12. TMB or tumor mutational burden (used to decide whether immunotherapy is the right treatment choice)
   13. NTRK
   14. I was tested but no biomarker was identified
   15. Other (specify) ____________________________
   16. I do not know

36. [ASK IF BIOMARKER TESTING DONE, CODES 1, 2, 3 IN Q24] What impact did biomarker testing have on your treatment decisions?
   1. I was put on a certain treatment called targeted therapy
   2. I was put on an immunotherapy
   3. I was put on an immunotherapy and chemotherapy
   4. I was enrolled in a clinical trial (please describe the treatment you received)
   5. I don’t know
   6. Other

37. [ASK IF BIOMARKER TESTING DONE, CODES 1, 2, 3 IN Q24] Since receiving biomarker testing, which members of your healthcare team have mentioned or referenced your biomarker testing results during a doctor’s appointment?
   1. Oncologist
   2. Pulmonologist
   3. Surgeon
   4. Nurse
   5. Nurse Navigator
   6. Palliative care team
   7. Radiologist
   8. My regular doctor/primary care physician
   9. Other (please specify: ____________________)
38. [ASK IF BIOMARKER TESTING DONE, CODES 1, 2, 3 IN Q24] Prior to biomarker testing, did you find out about specific costs you would have to pay for the testing?
   1. Yes
   2. No
   3. Not sure
   4. I didn’t have testing done

39. [ASK IF BIOMARKER TESTING DONE, CODES 1, 2, 3 IN Q24] How was your biomarker testing paid for?
   [ROTATE 1 AND 2]
   1. I paid the entire cost
   2. My health insurance paid the entire cost
   3. A non-profit or health charity paid the entire cost
   4. I paid some of the cost (a combination of insurance or non-profit/health charity and myself)
   5. Other (Please specify: ___________)
   6. I do not know

40. [ASK IF NOT COVERED BY INSURANCE Q39 NE 2] How affordable were the costs you had to pay for biomarker testing?
   1. Very affordable
   2. Affordable
   3. Reasonable
   4. Expensive
   5. Very Expensive

41. [ASK IF NOT COVERED BY INSURANCE Q39 NE 2] How much did the cost you had to pay impact your decision to have biomarker testing performed on you?
   1. A great deal
   2. Some
   3. Not too much
   4. Not at all
   5. Not sure/can’t recall

42. [ASK IF BIOMARKER TESTING DONE, CODES 1, 2, 3 IN Q24 AND HAVE INSURANCE Q6=1 AND/OR Q7=1-9] Did you encounter any difficulty or resistance from the insurance company to pay for the biomarker testing?
   1. Yes, a great deal
   2. Yes, some
   3. No, not too much
   4. None at all
   5. I don’t know

43. [ASK IF BIOMARKER TESTING DONE, CODES 1, 2, 3 IN Q24] Are you aware of any programs that help patients pay for biomarker testing? If so, please include the name of the program.
   1. Yes, and I used a program to help cover the cost (Program name: ___________)
   2. Yes, but I have not used a program to help cover the cost (Program name: ___________)
   3. No, I am not aware of a program to help cover the cost
   4. I do not know

44. [ASK IF BIOMARKER TESTING DONE, CODES 1, 2, 3 IN Q24] Were you offered assistance from a financial navigator (free service through the hospital) to help find out ways to pay for the cost of the test?
   1. Yes
   2. No
45. [ASK IF BIOMARKER TESTING DONE, CODES 1, 2, 3 IN Q24] In what areas did you feel you needed more information about the costs associated with biomarker testing? Select all that apply.

RANDOMIZE
a. The amount I would have to pay for the visit to the doctor’s office (co-pay)
b. The cost I would have to cover for the actual testing
c. Costs associated with follow-up visits to my doctor after testing
d. Costs for transportation to appointments
e. Costs associated with getting an additional biopsy
f. Costs associated with taking time off from work to get biopsy/tested
g. Costs associated with my caregiver taking time off from work to help with biopsy/testing appointments
h. Costs associated with childcare while I was at the appointment
i. Costs associated with treatment of my cancer due to the information from the test
j. [ANCHOR] Other: [Please describe: ____________]
k. [ANCHOR, EXCLUSIVE] None of these

46. [ASK IF BIOMARKER TESTING DONE, CODES 1, 2, 3 IN Q24] Who did you speak with about the costs of biomarker testing? Select all that apply.
   1. Doctor (any of the doctors on your care team)
   2. Nurse
   3. Receptionist/Front Desk staff
   4. Patient care coordinator/navigator
   5. Social worker
   6. Billing manager at your doctor’s office
   7. Insurance company
   8. I did not speak to anyone about costs

WHEN BIOMARKER TESTING IS NOT DONE

47. [ASK IF DISCUSSED WITH HCP BUT NOT DONE, CODE 3 IN Q21] Did your doctor or other healthcare professional explain to you why you did not or should not have biomarker testing?
   1. Yes, and I understand why biomarker testing was not done
   2. Yes, but I do not understand why biomarker testing was not done
   3. No, it was not explained to me
   4. I chose not to have biomarker testing done
   5. I do not know

IF Q48 NE 4]
48. Please indicate your level of confidence in asking your doctor why biomarker testing was not performed.
   1. Very confident
   2. Somewhat confident
   3. Neither/neutral
   4. Not too confident
   5. Not confident at all

49. [ASK IF NEUTRAL/NOT CONFIDENT, Q49=3,4,5] Please indicate the reason(s) for your lack of confidence when speaking with your doctor about biomarker testing. Select all that apply.
   RANDOMIZE
   1. I do not have a good relationship with doctor
   2. I do not understand medical language
   3. I am not comfortable speaking in English with my doctor
   4. I feel rushed during doctor appointments
   5. I do not feel comfortable asking questions of my doctor because it may affect my treatment.
6. [ANCHOR] Other [PLEASE DESCRIBE: ___________________]

50. [ASK IF NEUTRAL/NOT CONFIDENT, Q49=3,4,5] Did you consider speaking to another doctor about biomarker testing?
   1. Yes, I talked to a different doctor about testing to try to learn more information
   2. No, I didn’t know I should consider speaking to another doctor about testing
   3. Yes, I considered seeking information from a different doctor but didn’t have the means to find one/see another doctor
   4. Other [PLEASE DESCRIBE: ___________________]

51. [ASK IF Q48=1 OR 4 ABOVE] What was the reason(s) you did not have biomarker testing done? [OPEN END]

52. [ASK IF DISCUSSED WITH HCP BUT NOT DONE, CODE 3 IN Q21] How well did you feel you were able to ask questions and advocate for yourself regarding getting biomarker testing?

53. Which if any of the following were questions or concerns you had when considering biomarker testing? Select all that apply.
   1. Risks of the testing
   2. What results would mean for your treatment plan
   3. How frequently the testing is required
   4. The cost of the testing/ability to pay for it
   5. Whether your health insurance would cover the cost
   6. The cost of a targeted therapy if I was found to have a biomarker
   7. OTHER: [PLEASE DESCRIBE: _________________________________________________]

UNDERSTANDING BIOMARKER TESTING RESULTS

54. [ASK IF BIOMARKER TESTING DONE, CODES 1, 2, 3 IN Q24] How much do you agree or disagree with each of the following statements about your biomarker testing?
   1. Strongly agree
   2. Somewhat agree
   3. Neutral
   4. Somewhat disagree
   5. Strongly disagree

   [RANDOMIZE]
   a. The process of biomarker testing was clearly explained to me before I was tested
   b. My questions about biomarker testing were answered before I was tested
   c. I understood how the information would be used to make decisions about my treatment
   d. I made better decisions about my own care based on the results of the biomarker testing
   e. It gave me some peace of mind that the care team was doing everything possible to treat my specific type of lung cancer

55. [ASK IF BIOMARKER TESTING DONE, CODES 1, 2, 3 IN Q24] Which best describes your understanding of the explanation your doctor gave you about your biomarker testing?
   1. I understood the terms my doctor used to speak to me about biomarker testing
   2. I didn’t understand the terms my doctor used, but asked questions to clarify
   3. I didn’t understand the terms my doctor used, and didn’t ask questions to clarify

For people who answered 2 or 3 above, please ask
56A. If the terms were difficult to understand, what would have made them easier? Select all that apply.
1. Having the doctor use a written explanation
2. Having the doctor explain the terms with pictures
3. Having someone translate/interpret in my native language
4. Other _________________________

56. After getting your biomarker testing results, how well informed did you feel about what the results meant for your treatment?
1. Very well informed
2. Somewhat informed
3. Neutral
4. Somewhat uninformed
5. Very uninformed
6. Not sure

57. Did your doctor or another healthcare professional explain the results of your biomarker testing to you?
1. Yes, my doctor explained the results to me
2. Yes, another healthcare professional explained the results to me
3. No, my results were not explained to me
4. I don’t know/can’t recall

58. If you could talk to your health care provider/team about getting biomarker testing at this point in your care, what would you want to ask them? What would you find helpful? [OPEN-END]

60. Please rank up to three ways that would be most helpful to you to learn about biomarker testing and treatment options. Please mark the most helpful way with a 1, the second most helpful with a 2, and the third most helpful with a 3.

DEMOGRAPHICS

Last, a few questions for classification purposes.

61. What is your current gender identity? (Select one.)
1. Female
2. Male
3. Transgender Male/ Trans Man/FTM
4. Transgender Female/Trans Woman/ MTF
5. Gender Queer
6. Something else, __________
7. Prefer not to disclose
62. What is your marital status? (Select one.)
   1. Married or domestic partnership
   2. Single, never married
   3. Widowed
   4. Divorced
   5. Prefer not to disclose

63. Do you have children? (Select one.)
   1. Yes
   2. No

64. Are you currently employed for pay? (Select one.)
   1. Yes, I have a full-time job
   2. Yes, I work part-time
   3. No, I am retired
   4. No, I am on disability
   5. No, I am a student
   6. No, I am a home maker
   7. Other (please specify) ________________________________________________

65. What is your level of education? (Select one.)
   1. Less than high school
   2. High school or GED graduate
   3. Some college or technical school
   4. College or technical school graduate
   5. Graduate/professional school

66. What is your primary language? Choose only one.
   1. English
   2. Spanish
   3. Mandarin
   4. Cantonese
   5. Other, please specify

67. Would you classify the area you live in to be predominantly...?
   1. Urban
   2. Suburban
   3. Small town/rural
   4. Other

68. Including yourself, how many people currently live in your household?  NUMERIC OPEN-END WITH REFUSED. LIMIT 0-20

69. We are very interested in conducting additional interviews with survey respondents about your experience with biomarker testing. Would you be interested in speaking with us? This is completely optional.
   1. Yes
   2. No