# WILLINGNESS FOR MULTIPLE BIOPSIES TO IMPROVE QUALITY OF LUNG CANCER CARE: UNDERSTANDING THE PATIENT PERSPECTIVE

A white paper by LUNGevity Foundation

## ACKNOWLEDGMENTS

LUNGevity is deeply indebted to the lung cancer survivor community for taking the time to share their perspectives and make this study possible.

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## ABOUT LUNGevity

LUNGevity, one of the nation's largest lung cancer non-profits, is dedicated to changing outcomes for people with lung cancer through research, education, and support.

We focus on research because the link between research spending and improved survival is clear. Survival rates have dramatically improved for colorectal, breast, and prostate cancers over the last several decades in step with the exponential growth in their research spending. Our goal is to accelerate progress for lung cancer in the same way, in order to dramatically improve on the current 17% five-year survival rate.

LUNGevity research investments focus on early detection, because survival rates rise when lung cancer is detected while still localized. We also focus on more effective treatment approaches—getting the right treatment to the right patient at the right time to help people with lung cancer live longer and better.

LUNGevity also provides a community of empowerment, support, and hope for everyone affected by lung cancer through our extensive educational resources, online peer-to-peer support, and in-person survivorship programs, as well as more than 80 grassroots awareness and fundraising events held from coast to coast each year.

For more information visit us at www.LUNGevity.org

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## EXECUTIVE SUMMARY

With six drugs approved by the Food and Drug Administration (FDA) for lung cancer treatment in 2015 alone, the landscape for lung cancer therapy is rapidly evolving. Several targeted therapies are already marketed for patients with ALK, EGFR or ROS1 mutations, and additional drugs for these and other mutations are being studied in clinical trials. Clinical effectiveness of these drugs relies on matching patients with the right therapy through biomarker testing or profiling (also referred to as molecular testing or genetic testing of the tumor). In addition, the first immunotherapy options are now available in the clinic, with some testing requirements in labeling. Coincident with the rapid growth of new therapies is the development of improved testing methods to detect known biomarkers and the identification of new biomarkers to improve treatment stratification.

A biopsy is typically required to conduct biomarker testing, and in many cases, the same biopsy used for diagnosis can also be used for biomarker testing.. If the tumor tests positive for a specific actionable mutation, then treatment with an FDA-approved targeted agent (if one exists) is typically started, or a patient can receive information about participating in a clinical study for investigational drugs. Despite an initial benefit, however, the lung cancer almost always develops resistance to the drug. Researchers have identified secondary mutations that cause resistance to the first treatment, making it important to check whether the cancer has developed new mutations. The next treatment option or eligibility for a clinical trial can then be determined. However, anecdotal evidence suggests that clinicians do not always recommend an additional biopsy because they believe that patients will not want to undergo this procedure again, or because the patient's health condition may not be conducive to another biopsy. We conducted a study in which we asked lung cancer survivors about their perspective on getting additional biopsies. Our primary goal was to find out whether patients were willing to undergo additional biopsies. We surveyed 340 lung cancer survivors.

Interestingly, three-quarters of the survivors surveyed indicated their willingness to have an additional biopsy regardless of whether they reported any pain or complications from their initial biopsy. Specifically, among the survivors who were willing to undergo an additional biopsy:

1) Almost all of the survivors (82%) would do so if it would help their health care team better match treatment to their specific cancer and personalize their care, versus just being told the test was to look for mutations. In other words, understanding the end benefit of having the test is an important piece of communication.
2) Although almost 50% reported pain or complications from their initial biopsy, this group indicated equal willingness to have another biopsy as those without any issues.
3) If the doctor were to recommend an additional biopsy or a biopsy after the start of treatment, nearly half would **definitely** undergo one. About two-thirds of the survivors felt that their doctor explained the reason for getting their initial biopsy really well. Both these findings highlight that patients value their doctor's opinion and rely on being educated by them. They also suggest we need to build on the education component of patient care.

In summary, this study reinforces the importance of a patient-centric model in medicine–one in which meaningful and timely information is provided to patients to enable them to be partners in their own care.

# INTRODUCTION

Today, we know that lung cancer is not one disease. *Lung cancer* describes many different types of cancer that start in the lung or related structures. It is caused by mutations in the DNA or other changes in the cells that make cancer cells grow in an uncontrolled manner (Johnson, Schiller, & Bunn, 2014). There are two different ways of describing what kind of lung cancer a person has: its histology—what the cells look like under a microscope—and its *molecular or biomarker profile*—the types of mutations and other changes found in the cancer (IASLC, 2013).

Non-small cell lung cancer (NSCLC) is the more common type of lung cancer, diagnosed in about 85% of people with lung cancer (Johnson et al., 2014; Thomas, Liu, Subramaniam, & Giaccone, 2015). Adenocarcinoma and squamous cell lung cancer are the most common subtypes of NSCLC (Chen, Fillmore, Hammerman, Kim, & Wong, 2014). The other type of lung cancer, small cell lung cancer (SCLC), is seen in about 15% of lung cancer cases.

The complex nature of lung cancer requires personalized management plans for patients (Johnson et al., 2014). The three mainstays of lung cancer treatment—chemotherapy, surgery, and radiation—are continually evolving. Now people with lung cancer may also have the option of chemotherapy, targeted therapy, angiogenesis inhibitors, or immunotherapy. Targeted therapy blocks molecular vulnerabilities in a cancer cell and stops the cancer cells from growing. Since the discovery of the first epidermal growth factor receptor (EGFR) mutation in lung cancer in 2004 (Lynch et al., 2004; Paez et al., 2004; Pao et al., 2004), we have come a long way – now at least 10 driver mutations in adenocarcinoma have been identified (EGFR, ALK, ROS, RET, ERB2/HER2 mutations, ERB2/HER2 amplifications, MET amplifications, MET mutations, TRK, BRAF, KRAS) (Devarakonda, Morgensztern, & Govindan, 2015) (Arcila, 2015). In concert with the identification of an increasing number of targetable mutations is the development of novel, more potent, and more specific targeted therapies. For example, at present, third generation EGFR (Cross et al., 2014) tyrosine kinase inhibitors (TKIs) and second generation anaplastic lymphoma kinase (ALK) TKIs (Isozaki, Takigawa, & Kiura, 2015) are used in clinical practice. In addition, the FDA just approved the use of crizotinib, a first generation ALK TKI which also targets ROS1, for the treatment of ROS1-positive lung cancers (FDA, 2016). Many other targeted therapies are being developed in clinical trials (Tsao et al., 2016).

Two other important types of drug treatment have also emerged in recent years--angiogenesis inhibitors (Guijarro-Munoz, Roarty, & Heymach, 2016) and immune checkpoint inhibitors (Brahmer et al., 2015; Garon et al., 2015). Neither has as strong a signal from biomarker testing as targeted therapies, although an immune checkpoint inhibitor on the market (Merck, 2015) has a requirement for biomarker testing in its label. Some immune checkpoint inhibitors in development also use a biomarker in clinical trials to assess the optimal patient profile. With

this progress in lung cancer therapy comes the need to identify the right patient for the right therapy – the ultimate goal of precision medicine.

At a minimum, patients with advanced-stage adenocarcinoma should be tested for EGFR and ALK – the first two mutations that had FDA-approved effective targeted therapies. The College of American Pathologists (CAP), the International Association for the Study of Lung Cancer (IASLC), and the Association of Molecular Pathologists (AMP) recommend analysis of either the primary tumor or of a metastasis for EGFR and ALK for all patients whose tumor contains an element of adenocarcinoma (Leighl et al., 2014; Lindeman et al., 2013). This is independent of the clinical characteristics of the patient. These guidelines are being revised to include some of the recently characterized targetable mutations such as ROS1, MET, ERBB2/HER2, RET, and NTRK1 (IASLC, 2015). Biomarker testing is performed on lung cancer tissue removed during a biopsy done using fine-needle aspiration, core needle, video-assisted thoracoscopic surgery (VATS) resections, surgery, bronchoscopy, or, in the case of lymph node sampling, during a mediastinoscopy (IASLC, 2013). Sometimes, cellblocks made from thoracenteses (plural fluid drainages) can be used to perform biomarker testing (Ofiara, Navasakulpong, Beaudoin, & Gonzalez, 2014). The tissue is then used for determining the histology of the cancer, which in turn decide course of treatment. As described above, tissue from advanced-stage adenocarcinoma patients should also be tested for EGFR mutations and ALK rearrangements.

However, additional lung cancer tissue may be required when:

1) Not enough tissue was obtained during the initial biopsy, and as a result biomarker testing was not performed
2) A targeted therapy that worked well against the cancer has stopped working and the cancer has recurred. Testing the resistant cancer for additional mutations that may have evolved (Yu et al., 2013) or rare changes in histology (Sequist et al., 2011) is indicated to help guide the oncologist toward the next best treatment, especially for EGFR and ALK patients, where 2$^{nd}$ and 3$^{rd}$ generation EGFR and ALK drugs can be chosen if the resistance mutations indicate they may be effective.
3) New drugs are approved for the treatment of lung cancer from which the patient might possibly benefit. The new drug or treatment might require biomarker testing.

Anecdotal evidence suggests that clinicians are making assumptions about patient needs (see below) and are disinclined to suggest multiple biopsies to their patients :

1) Reluctance on the patient's part due to pain during the first biopsy procedure and complications arising after the procedure
2) Lack of comprehensive health insurance coverage leading to issues with reimbursement by health insurance companies

We, therefore, wanted to understand the patient perspective about undergoing biopsies for improving their standard of lung cancer care. Specifically, we were interested in finding out:

1) What kind of information do lung cancer patients receive from their healthcare team about undergoing additional biopsies after treatment has started?
2) Under what circumstances are patients willing to undergo additional biopsy or a biopsy after treatment has started?

## APPROACH

We constructed an online structured survey with questions about a patient's perspective and willingness to undergo additional biopsies for lung cancer treatment. Information related to histology of lung cancer and disease stage at diagnosis was collected. For the purposes of this white paper, the word "re-biopsy" will be used to describe the following situations:

1) Obtaining a biopsy after treatment has started (when a biopsy was not recommended at the time of initial diagnosis)
2) Obtaining a biopsy after treatment has started (even when a biopsy was performed for initial recommendation of treatment)
3) Obtaining a biopsy at the time a treatment stops working to try to understand why the tumor initially responded to the therapy, but the stopped responding

Information on whether the biopsy was done on the primary tumor or a metastatic lesion was not collected.

The survey also provided an opportunity to probe what additional types of information patients sought from their health care providers, as well as reasons for lack of willingness to undergo additional biopsies. Participation in the survey was open to anyone who was living with a diagnosis of lung cancer, even if they showed no evidence of disease. Caregivers and healthcare professionals were excluded from answering the survey.

Survey respondents were recruited:

1) Through email invitation to survivors who had requested to receive electronic communication from LUNGevity
2) By posting a link of the electronic version of the survey on the Support and Survivorship Resources section of the LUNGevity website (http://www.LUNGevity.org/support-survivorship)

3) By posting a link of the electronic version of the survey on LUNGevity's social media page (Twitter and Facebook), and on Lung Cancer Support Community (LCSC)
4) Through email invitations to an independent research panel recruited by EdgeResearch. The research panel is a group of patients sampled for different diseases, and not specific to lung cancer. Our eligibility criteria made sure we sampled only lung cancer patients. Data collected from this group will henceforth be referred to as the "Research Panel"

Data was collected from October 8 to October 27, 2015. All data from the survey was tabulated in Microsoft Excel.

## MAJOR FINDINGS

We surveyed a total of 340 lung cancer survivors, 185 of whom were from the LUNGevity community and 155 of whom were sourced from EdgeResearch's online panel.

In brief:

1) The reported prevalence of different histological sub-types of lung cancer [for example around 15% SCLC (SEER, 2015)] matched available epidemiological data. Patients with lung adenocarcinoma were more represented among the LUNGevity survivor respondents (63% as against 9% from the research panel).
2) 66% of the respondents were women
3) 25% of the respondents were above the age of 65
4) 99% of the respondents had some form of health insurance coverage
5) 88% of the respondents identified themselves as white/Caucasian.

A detailed analysis of the survey respondents is presented in Appendix A.

### *Knowledge and experience with biopsy at time of diagnosis*

In the clinic, lung cancer is diagnosed through a combination of imaging and tissue-based tests (IASLC, 2013). Computerized tomography (CT) scans help in the detection of lung nodules or masses in symptomatic patients, or in people who belong to the high-risk population as defined by the National Lung Screening Trial (NLST) guidelines. Once a nodule is detected, a doctor may recommend additional imaging tests such as magnetic resonance imaging (MRI), 18F-fluorodeoxyglucose (18F-FDG) positron emission tomography (PET), and bone scans to stage the cancer (extent of spread to surrounding lymph nodes and metastasis). Metastatic lesions of lung cancer to the bone or brain are determined through a combination of 18F-FDG-PETand CT (D'Antonio et al., 2014). A pathologist then determines the histology of the lung cancer (NSCLC and its sub-types or SCLC) by examining a tissue sample under the microscope. If the pathologist determines that a patient has adenocarcinoma, then additional molecular testing

for EGFR or ALK mutations should be undertaken. In addition, the National Comprehensive Cancer Network (NCCN) guidelines recommend broader molecular profiling with the goal of identifying rare driver mutations for which effective drugs may already be available or being tested in clinical trials (NCCN, 2016). These rare driver mutations include BRAF V600E mutation, high-level MET amplification or MET exon 14 skipping mutation, RET rearrangements, ROS1 rearrangements, and ERB2/HER2 mutations. If the patient has squamous cell lung cancer, then the oncologist might recommend participation in Lung-MAP, a squamous cell lung cancer-specific clinical trial program (clinical trial # NCT02154490). In this trial, patients undergo molecular testing and are matched with the drug intended to treat their particular mutation if they have one (Lung-MAP, 2016). In addition, PD-L1 testing to potentially stratify patients to the immunotherapy arm is also recommended. Both histological classification and biomarker testing require cancer tissue samples.

In the first part of the survey, we asked respondents about diagnostic procedures they had undergone. Almost all respondents had undergone a CT scan (91%) or a PET scan (67%) at the time of diagnosis (Figure 1). **Sixty-eight percent** (N = 231) of the respondents had undergone an invasive biopsy procedure such as a needle or a surgical biopsy; 16 % of respondents had undergone both procedures. One hundred and nine respondents (32%) reported never having undergone a biopsy procedure. Other diagnostic tests that were reported by some respondents include bone scans for metastasis, thoracentesis, thoracotomy, and sputum cytology.

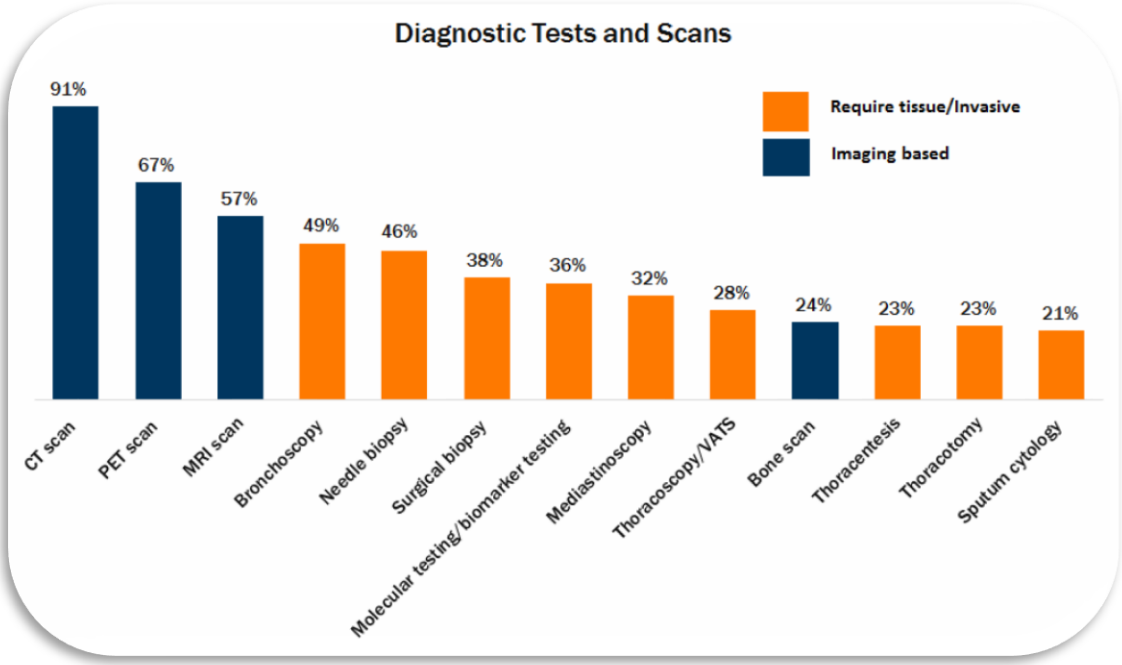


**Figure 1**: **Scans and tests prescribed by healthcare professionals at the time of lung cancer diagnosis.. Total sample size N = 340**

As expected, we observed a small correlation between having a biopsy and other diagnostic procedures. The respondents who underwent biopsies were more likely to receive other diagnostic evaluations listed in Figure 1. However, mediastinoscopies were more frequently prescribed to patients less likely to have undergone a biopsy at the time of diagnosis.

Respondents who underwent a biopsy (N = 231) were also asked about the reasons given by their healthcare team about the need for a biopsy at the time of diagnosis. The majority of the respondents were told that a biopsy was needed to confirm the presence of lung cancer (Figure 2). Physicians also told their patients that biopsies were necessary to determine the histology, as well as the stage, of the cancer. However, only about one-fifth of the respondents were told that a biopsy was necessary to conduct biomarker/molecular testing – to check for the presence of known actionable mutations – and the smallest percentage recalled being told that the biopsy would help determine eligibility for specific treatments.

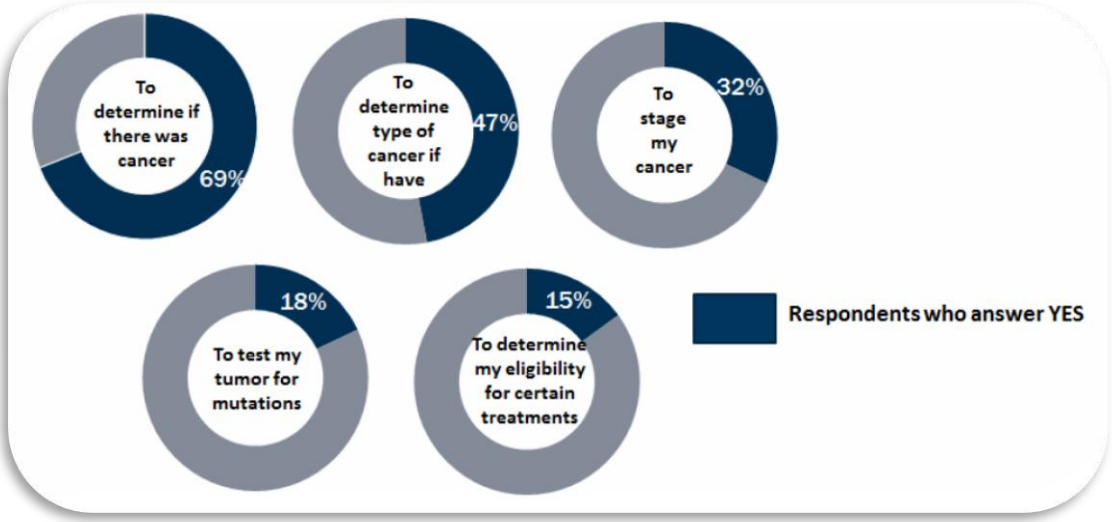


**Figure 2**: **Reasons provided by healthcare professionals for biopsy at the time of diagnosis (N = 231)**

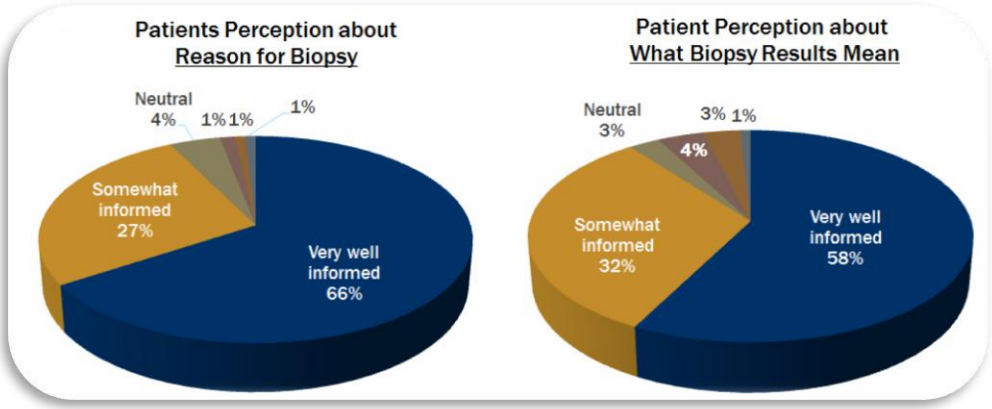


**Figure 3**: **Patient's perceived knowledge of biopsy procedure at the time of diagnosis**

While physicians may be providing information to their patients, it is important to understand whether this information is leading to increased understanding about the biopsy process, and helping patients be active participants in their treatment decision

Of the patients who underwent a biopsy at the time of diagnosis, about **two-thirds** of them felt very well-informed about the reasons why their doctors prescribed a biopsy. Furthermore, 58% of the respondents also felt that their physicians explained the results of their biopsy adequately.

We also wanted to understand how patients felt about their initial biopsy experience and whether, in their opinion, it impacted the quality of care they received (Figure 4). Overall, respondents reported a positive initial biopsy experience. They felt that they adequately understood the role of a biopsy in making treatment decisions, and the health risks associated with conducting a biopsy. When probed about the physical experience of undergoing a biopsy (N=231), 42% of the respondents reported their experience to be a painful one, and 22% had experienced complications as a result of the procedure.

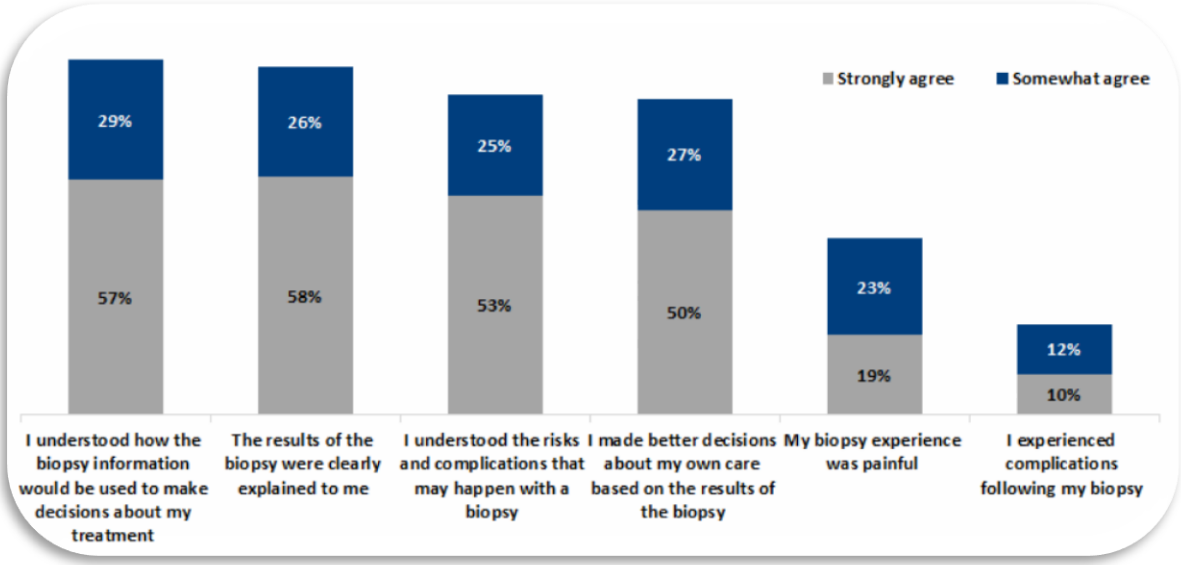


**Figure 4**: **Respondent's biopsy experience at the time of diagnosis (N = 231)**

The first section of the study demonstrates that among those who had a biopsy, most felt well-informed about the role of a biopsy in treatment decision-making by their healthcare practitioner.

## *Attitude and experience with re-biopsy*

A lung cancer patient may require additional biopsies if there is a recurrence of the cancer after initial treatment, or if adequate tissue was not obtained in the first biopsy. Typically the oncologist decides whether a second biopsy is required. The 109 respondents (32%) who had NOT undergone a biopsy at the time of diagnosis were more likely to receive a recommendation for a biopsy after treatment (53% of the 109 respondents received a biopsy recommendation) Of the 231 patients (68%) who had had a biopsy at the time of diagnosis, only 36% reported receiving a re-biopsy recommendation from their healthcare team. This might be due to the fact that either the patient has a diagnosis of SCLC, or no mutations were detected in the initial biopsy.

Healthcare professionals are less likely to suggest additional biopsies to those patients that have had a previous biopsy. Of all the patients surveyed, 15% received no recommendation for a biopsy at **any time** during their treatment.

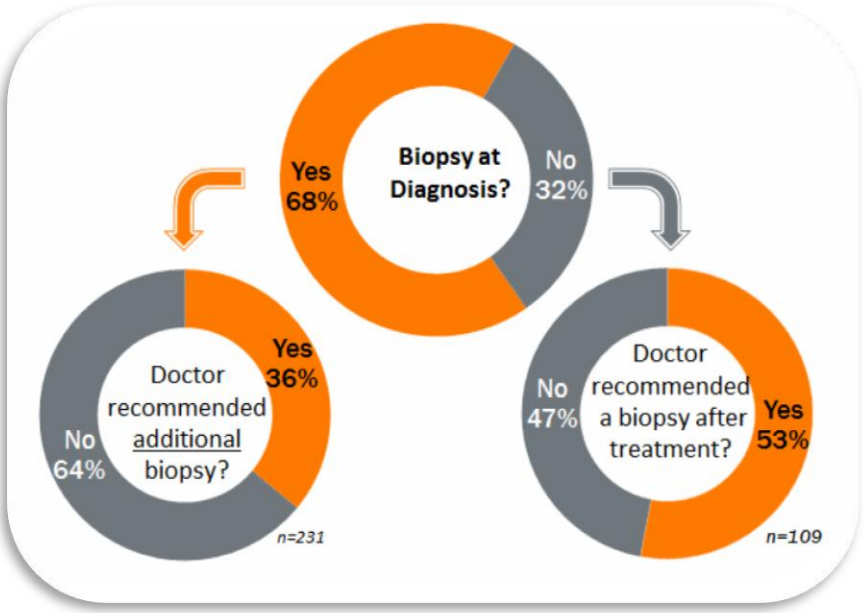


**Figure 5**: **Physician recommendation, either for an additional biopsy or a biopsy AFTER treatment has started**

Respondents were then asked about the reasons provided by their healthcare team for either a re-biopsy or a biopsy after the commencement of treatment (for those who had not had one at the time of diagnosis). Physicians in both groups of respondents cited biomarker testing or molecular profiling as the primary reason for need of an additional biopsy (Figure 6). About a third of the respondents reported that their cancer needed to be-restaged.

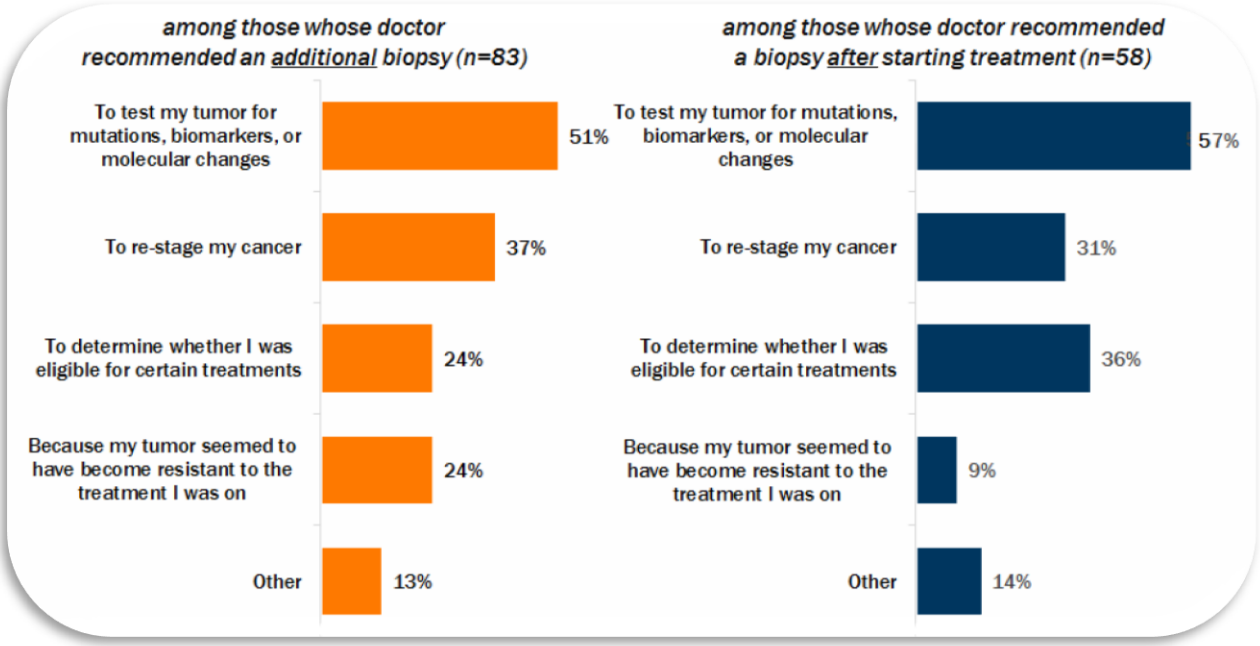


**Figure 6**: **Physician-cited reasons for undergoing a re-biopsy or a biopsy after commencement of treatment**

It is important to understand whether physician-provided information is useful in equipping the patient community with the right kind of knowledge to feel empowered about making their treatment decisions. Both groups of respondents (those who received a recommendation for an additional biopsy, or a biopsy after the commencement of the treatment) felt that their healthcare team had provided them adequate information to make a decision regarding their treatment.

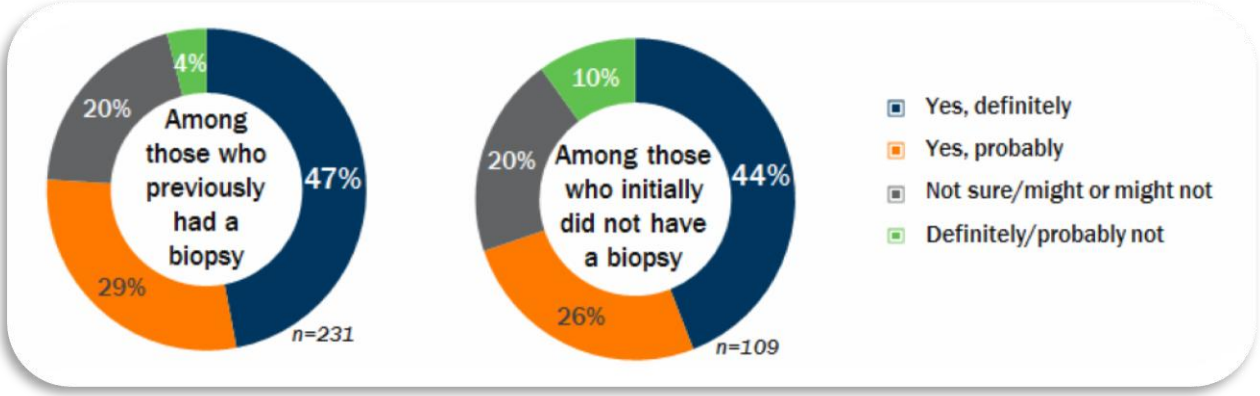


**Figure 7**: **Respondent preference to undergoing a biopsy at this point in their treatment**

In the last part of the study, we asked our respondents whether they would be willing to have a biopsy at this point in their treatment. This included both the groups who had a prior biopsy,

and those who had never had a biopsy before. Interestingly, nearly **three-quarters** of the respondents would undergo biopsy if their healthcare team recommended one (Figure 7).

Furthermore, a respondent's previous experience with a biopsy (painful biopsy or complications arising due to the procedure) did not affect their willingness to undergo an additional biopsy. Seventy-six percent of patients who had a painful biopsy, and 82% of patients who had experienced complications were willing to have additional biopsies if their healthcare team recommended it (Figure 8).

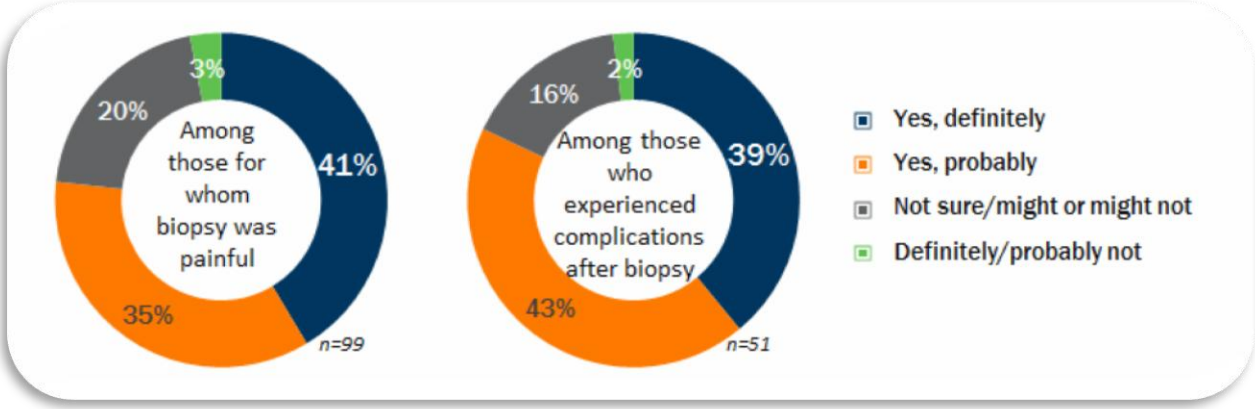


**Figure 8**: **Respondent willingness to have additional biopsy stratified by previous biopsy experience**

We also asked respondents the primary reason for undergoing additional biopsies (Figure 9). Getting more personalized treatment was cited as the strongest rationale for having an additional biopsy or a biopsy after treatment. Additionally, respondents felt that an additional biopsy would provide tissue samples to conduct biomarker testing – a prerequisite to getting matched to the appropriate targeted therapy. The possibility of having the option of an at-home treatment regimen such as an oral medication, over infusions that require regular doctor office visits, was also a priority for the respondents.

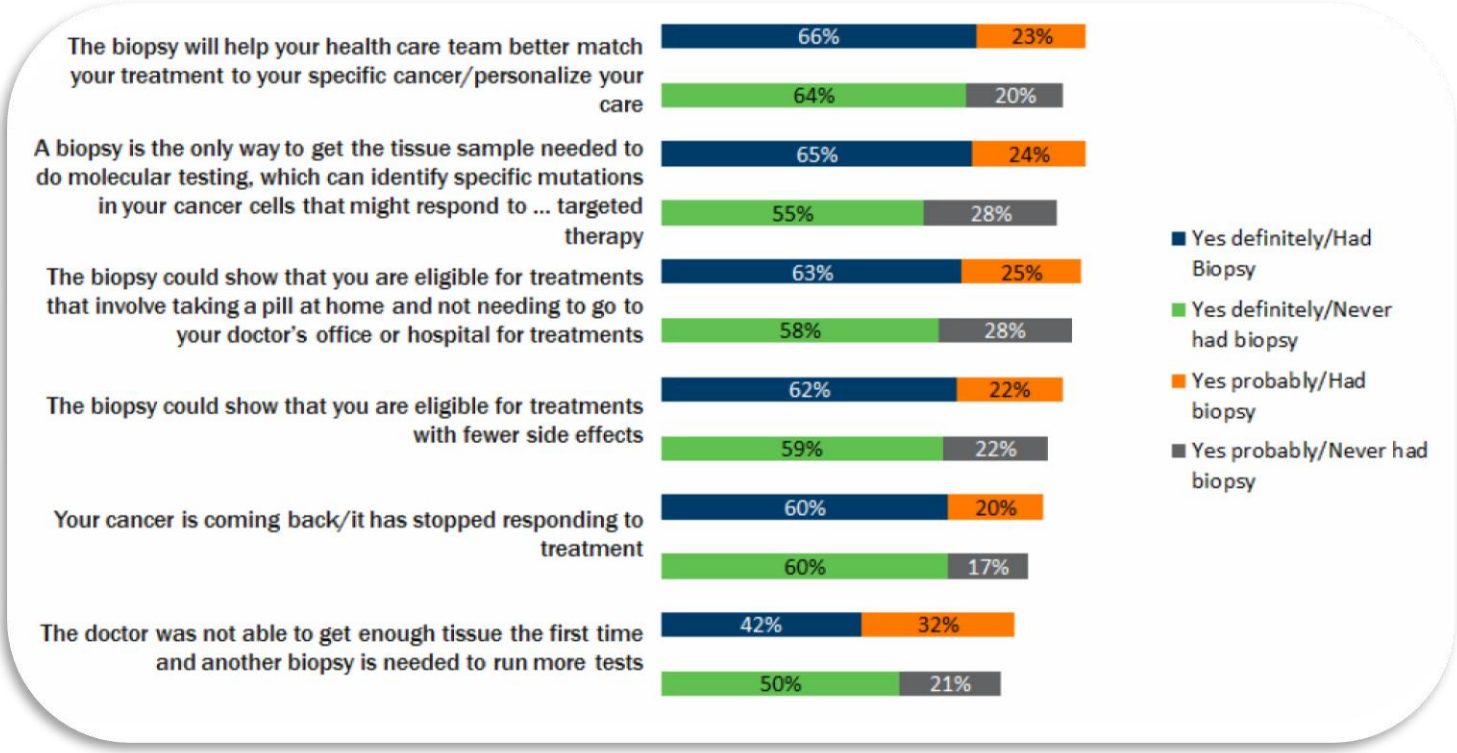


**Figure 9**: **Major reasons for undergoing an additional biopsy**

Respondents also reported why they were unwilling to undergo additional biopsies, as responses to an open-ended question. The reasons cited fall into three major themes. Representative quotes associated with each theme are shown in Figure 10.

**Treatment-specific**: Respondents were willing to undergo a biopsy ONLY if it meant that they would have access to novel treatments. They hoped that their physician would explain these choices.

**Procedure-specific**: Pain during the procedure and scarring at the site of biopsy were often cited as major barriers to undergoing additional biopsies

**Patient-specific**: Some respondents reported that their health condition would not allow for additional biopsies.

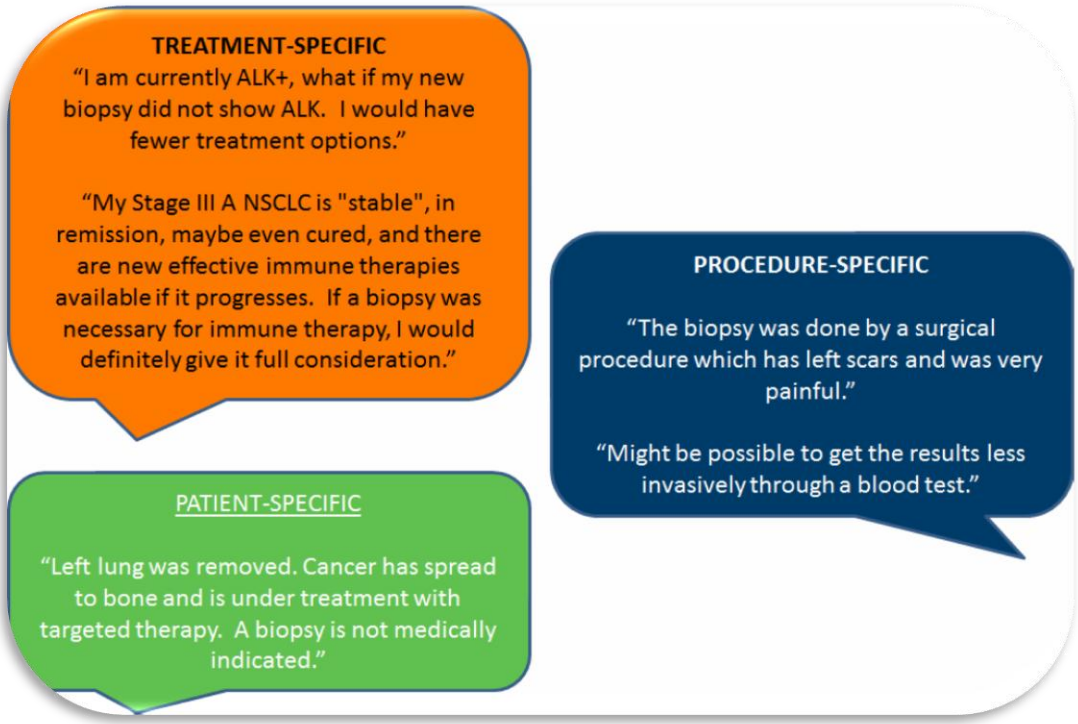


**Figure 10**: **Major reasons cited for not willing to undergo an additional biopsy**

To get a true patient perspective, we also asked the respondents about additional types of information that their healthcare team could provide, to help them become equal partners in their care. The responses can be classified into three main themes.

**Treatment-specific**: Knowledge about potential treatment options and how having an additional biopsy would open up new treatment options were of paramount importance to respondents.
**Procedure-specific**: Respondents also expressed concerns about the process of undergoing an additional biopsy and wanted the opportunity to ask their healthcare providers about the duration, usefulness, cost and potential risks associated with the procedure.
**Benefits-Risk-specific**: Finally, respondents expressed a wish to discuss how an additional biopsy would improve their outcome with their healthcare team.

Almost all respondents felt that having more information about the biopsy procedure itself and the benefits of the re-biopsy definitely would influence their decision of getting an additional biopsy.

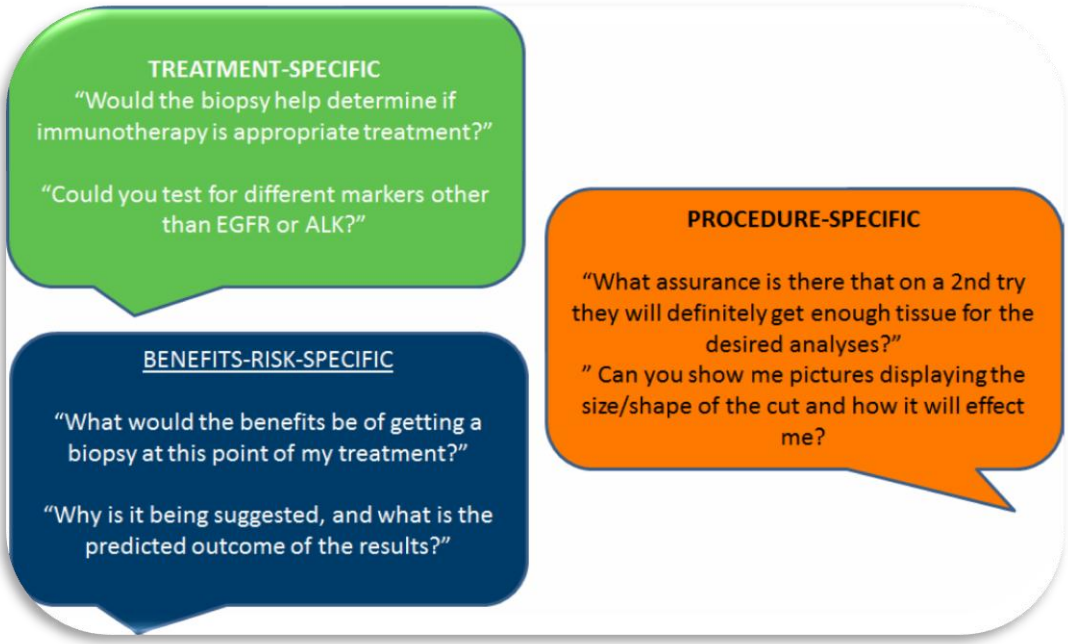


**Figure 11: Questions/Considerations for undergoing additional biopsies**

## CONCLUSIONS

Our study demonstrates that the benefits of biopsy are perceived to outweigh the negative experience (pain during procedure and complications after procedure). A majority of the patients feel well informed about the need for an initial biopsy, as well as about what the results might mean. Importantly, most patients who have a biopsy feel it led to making better treatment decisions.

We also found that the majority of patients are willing to undergo an additional biopsy or a biopsy after treatment if their doctor recommends it; and nearly half are very willing. Even those who experienced pain or complications during a previous biopsy are open to another.

When doctors recommend a biopsy after the start of treatment they are most likely to cite the "need to test for mutations, biomarkers or molecular changes" as the reason for doing so. When reasons for getting a biopsy, as well as how the results from a biopsy will drive treatment, are explained to patients, they feel educated and empowered.

Whether an additional biopsy or a biopsy after treatment has started is useful for deciding treatment strategy for a lung cancer patient should be ultimately decided by the healthcare provider. The lung is a vital organ, and biopsy of the lung is associated with potential complications such as pneumothorax, hemoptysis, air embolism, seeding of the biopsy tract,

and death (Lorenz & Blum, 2006). Furthermore, the patient's health status or lung function may not allow for additional biopsies.

Despite these challenges a biopsy is often necessary to decide the best course of treatment for a patient. The decision to undergo one should be made jointly by the patient and the healthcare provider.

## LIMITATIONS OF THE STUDY

We noted the following limitations of the study:

1) Capturing the effects of race and ethnicity: Our sample is predominantly white/Caucasian, suggesting that the voices of other races and ethnicities may not be adequately represented in the findings.
2) Age of respondents: Lung and bronchus cancer is most frequently diagnosed among people aged 65-74 (SEER, 2015). More than half (58.6%) of lung cancers are diagnosed above the age of 65. In our sample, only 25% of the respondents were above the age of 65, suggesting that the sample may not accurately reflect age distribution of lung cancer. This may be due to the use of an online survey that would be answered be a younger, more computer-literate demographic.
3) Effects of access to care: Most of our survey respondents had some form of health insurance suggesting that financial constraints may not have been of paramount importance. Geographical generalization and effect of computer literacy: The study surveyed patients in continental USA and was survey-based; therefore, the opinions captured in this study may not reflect that of lung cancer patients globally. Also, only those survivors with access to email and social media as well as computers would be preferentially captured in this survey.

Despite these limitations, the study highlights the importance of the patient perspective in the lung cancer treatment decision-making process, and willingness of patients to undergo additional biopsies and have to access to personalized medicine

# APPENDIX A

**Characteristic of the survey respondents**

| | | Total (N = 340) |
|---|---|---|
| **GENDER** | Male | 34% |
| | Female | 66% |
| **AGE (in years)** | Under 18 | - |
| | 18 to 34 | 17% |
| | 35 to 44 | 13% |
| | 45 to 54 | 16% |
| | 55 to 64 | 29% |
| | 65 to 74 | 20% |
| | 75 or older | 5% |
| | Mean | 52.6 |
| **TIME FROM DIAGNOSIS** | Less than 6 months | 8% |
| | 6 months to 11 months | 10% |
| | 1 year to less than 2 years | 23% |
| | 2 years to less than 3 years | 22% |
| | 3 years to less than 5 years | 15% |
| | 5 years to less than 10 years | 17% |
| | 10 years or more | 6% |
| | Not sure | 0% |
| **HISTOLOGY AT TIME OF DIAGNOSIS** | Adenocarcinoma | 38% |
| | Squamous cell | 11% |
| | Large cell | 12% |
| | Carcinoid | 5% |
| | Not sure of type but know it was non-small cell lung cancer | 9% |
| | Small cell lung cancer (SCLC) | 15% |
| | Other, please specify: | 3% |
| | Not sure | 6% |
| **STAGE AT TIME OF DIAGNOSIS** | Stage I | 21% |
| | Stage II | 24% |
| | Stage III | 19% |
| | Stage IV | 28% |
| | Limited stage | 1% |
| | Extensive stage | 1% |
| | Not sure of stage, but it was “localized” | 4% |
| | Not sure of stage, but it was “non-localized” | - |
| | Did not discuss the stage with my doctor | 1% |
| | Not sure | 1% |
| **HEALTH INSURANCE** | Coverage through your current or former employer or spouse’s employer or union | 56% |

| | | |
|---|---|---|
| **STATUS** | Coverage purchased directly from health insurance company (you pay for it yourself) | 18% |
| | Medicare – insurance program for seniors | 31% |
| | Medicaid – insurance provided through the state for low-income families | 11% |
| | Coverage through your parents' health insurance | 2% |
| | No health insurance coverage | 1% |
| | Other | 7% |
| **RACE** | White/Caucasian | 88% |
| | Black/African American | 4% |
| | Asian, Pacific Islander | 3% |
| | American Indian | 0% |
| | Other | 3% |
| | Prefer not to answer | 3% |

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