# Understanding the Patient Experience With Biomarker Testing Results Reports in Lung Cancer *Findings from Patient and Provider Focus Groups*

June 2022





## ABSTRACT

The growing number of FDA-approved targeted therapies have made biomarker testing a critical aspect of lung cancer care, informing both choice of therapy and prognosis. However, complex biomarker test reports filled with unfamiliar medical terminology can confuse patients and cause anxiety, presenting challenges for both the patients and their healthcare teams. To characterize unmet needs related to biomarker testing reports in lung cancer, LUNGevity conducted separate focus groups with patients and providers to better understand the perspectives and experiences of each group with biomarker testing. Results from this analysis showed that although their experiences with biomarker testing varied widely, patients shared a need for support with interpreting complex biomarker test results reports. Physicians recognized this need among their patients, and also shared their own challenges with accessing and interpreting lengthy reports. Here we summarize the patient experience with biomarker testing in lung cancer and highlight unmet needs from both the patient and provider perspectives. We also share recommendations from patients and providers for improving biomarker test reports and developing resources to support patients with interpreting their results.

# OVERVIEW AND METHODOLOGY

Targeted therapies have revolutionized treatment of lung cancer, resulting in improved outcomes for patients (Skouldis and Heymach 2020; Chu 2020). Because selection of the appropriate targeted therapy relies on understanding the unique characteristics of an individual's tumor, biomarker testing has become an essential part of lung cancer management (Chu 2020; König et al. 2021). However, complex biomarker reports characterizing large numbers of genomic variants present a challenge for patients and healthcare providers (HCPs) trying to derive meaningful and actionable information from the results (Martin et al. 2021;). Providing support to help patients better understand the information presented in their biomarker test reports can ensure that patients get the answers they need for questions related to their cancer and their care.



"I can't spend my whole time being the patient, being the patient advocate, being the patient medical adviser and dealing with the insurance denying standard of care practices. It's just too overwhelming, and I wish doctors... I mean, they could give you a handout, it doesn't have to be a big verbal conversation, but they just, they don't."

**GENERAL PATIENT** 

LUNGevity aims to improve outcomes for people with lung cancer by empowering them to be active participants in shared decision-making with their multidisciplinary healthcare team. Given the important implications of biomarkers in lung cancer, strategies for helping patients better understand biomarker testing reports may contribute to more productive discussions between patients and providers about treatment.

LUNGevity conducted this research to identify strategies for better supporting patients with understanding their biomarker test results. This qualitative analysis probed patient and provider perspectives on biomarker test reports and explored whether specific structural aspects and/or components of these reports are particularly confusing or frequently misunderstood by patients. Results from this study have enabled us to create targeted educational resources designed to help patients better understand their reports and guide dialogue between patients and their healthcare team, thereby improving the experiences of the lung cancer community.

#### OBJECTIVES

The objectives of this study were:

- To document the experiences of patients undergoing biomarker testing for lung cancer in order to identify their unmet needs
- To understand how these needs align with healthcare provider (HCP) objectives for shared decision-making about treatment

### Approach and Methodology

In April 2022, LUNGevity convened 2 focus groups of patients with lung cancer. Patients selected to participate in focus groups were familiar with biomarker testing and could confirm that they had been tested. The first group included 6 patients with LUNGevity connections and the second group included 6

patients with no connections to LUNGevity, all of whom had undergone biomarker testing. During the focus group, an independent moderator asked a series of questions about patients' experiences with receiving and interpreting biomarker test results and about their interactions with HCPs related to biomarker testing. Patients also identified confusing and unclear aspects of their own biomarker test reports and reviewed hypothetical reports with varying structures shared by the moderator.

LUNGevity also hosted 2 discussions with multidisciplinary groups of HCPs in May 2022. Participants included a thoracic medical oncologist, a clinical pharmacist practitioner, a nurse practitioner, and an oncology nurse practitioner and faculty member. In these focus groups, the HCPs shared their experiences with ordering and receiving biomarker test reports, summarized typical interactions with patients, and outlined needs for patient education.

In this summary are the focus group findings, highlighting the wide variety of patient experiences with biomarker testing, challenges in understanding and interpreting reports, and unmet needs within biomarker testing results reports from the patient and provider perspectives.

# FINDINGS

### Patient Experiences With Biomarker Testing Vary Widely

From the initial conversations with their healthcare team, decision-making around biomarker testing was a highly individualized process. Consistent with the results of previous LUNGevity-led patient research (Martin et al. 2022), patients reported differences in the timing of testing, who initiated discussions about testing, and the amount and quality of pre-test discussion. These differences correlated to some extent with physician style and approach to treatment. Patients also had varying experiences with receiving their results, with some patients receiving their results from their providers and others receiving their results from a patient portal before meeting with their team. Others received the findings from their biomarker testing during a conversation with their provider but never received a physical copy of their results.

In addition to having different experiences with testing and receiving their results, patients also had different preferences about the amount of information they were comfortable with receiving. Some patients felt overwhelmed by too much information and relied on the judgment of their healthcare team, while others preferred to know all they could, using their reports as a starting point to research their disease and potential treatments. In addition to discussions with their healthcare team, these patients relied on web-based resources like PubMed, educational materials from LUNGevity and other patient advocacy groups, and knowledgeable individuals from family and support networks to interpret their results.

Despite these different experiences and needs, there was broad agreement among patients that biomarker testing was critical for making decisions about lung cancer treatment. However, patients felt that the reports were often confusing and difficult to understand. They suggested that summarizing the information in their reports using language and formatting targeted to a more general audience would make the results more accessible to patients. They also identified many aspects of biomarker test reports that could benefit from additional explanation, including the language and terminology used in the report, prioritization of biomarker findings and treatments, and the implications of the results beyond initial

treatment selection. To better understand how these strategies could meet the needs of patients undergoing biomarker testing, the next section of the report provides a detailed review of the patient journey with biomarker testing, from initiating discussions about testing to receiving the results and discussing them with the healthcare team.

### Understanding the Patient Journey With Biomarker Testing

#### Initiating the Discussion About Biomarker Testing

Discussing biomarker testing with the healthcare team was recognized as an important part of the decision-making process for patients with lung cancer, but how these conversations were initiated and who initiated them varied. Some patients, particularly those with more recent diagnoses, said that their providers raised the issue of biomarker testing at the outset, either prior to treatment or at recurrence for those who were diagnosed decades earlier. During these discussions, some patients shared that their HCPs highlighted the importance of waiting for the results of biomarker testing to finalize the treatment plan, which can be challenging for patients who are anxious to begin treatment.



"It came up on my very first visit with the oncologist. He explained to me that I could either start chemo right then, right away, or I could wait 2 to 4 weeks until this biomarker testing. And he explained to me that it would give him a better idea of the type of cancer that I had and the type of treatment. He actually drew me a little diagram, which I still have it here, telling me what each form of treatment would be, what the side effects of each would be."

PATIENT WITH A LUNGEVITY CONNECTION

In other cases, the patients were the first to raise the issue of biomarker testing in discussions with their physicians. Patients reported bringing up biomarker testing on the advice of family members or because of a family history of cancer.



"Actually it was because of my daughters. When I first got diagnosed, the next appointment my daughters went with me, and I mean, I didn't know what to ask. When he said what kind of testing they were going to do, it was never mentioned, and my daughter's the one who brought it up. She said, 'Well, I heard that there's the biomarkers. My grandfather had stomach cancer and my aunt and my uncle...' He was probably wanting to take the time, not jump the till I started having more issues.... He never mentioned the biomarkers till my daughter brought it up."

#### GENERAL PATIENT

Some patients did not discuss biomarker testing with their healthcare team during their initial consultations, but were subsequently offered testing. In one example, a patient was not offered testing until seeking a second opinion from an oncologist in an academic cancer center. Another patient shared that targetable biomarkers were identified after they completed chemotherapy and radiation treatment for central nervous system disease. Other patients who raised the idea of biomarker testing with their

physicians were told that they did not need to be tested. Reasons for not recommending testing included squamous tumor histology and completion of treatment with no evidence of disease.



"Well, when I first diagnosed, I knew nothing about it, and the doctor said nothing about it. And he had a treatment plan, and we followed the treatment plan. So that was 2013. From 2015, I started learning about biomarkers and IDs and everything. So, I had asked my doctor when my cancer come back the third time, I said, 'What about testing biomarkers?' He said, 'You don't need it. You're squamous.' I said, 'I don't need it? That's what that makes treatment more personal.' He said, 'Squamous don't need it. They don't have markers.' Well, I learned later on they do have markers."

PATIENT WITH A LUNGEVITY CONNECTION

Based on these discussions with their healthcare teams, patients reported several reasons for choosing to undergo testing. Several patients highlighted the importance of biomarker testing as a key factor for defining the treatment plan and selecting an appropriate targeted therapy. However, some patients cited additional reasons beyond treatment. For example, a patient who had never smoked noted the importance of biomarker testing in understanding the underlying genetic drivers of the cancer. Other patients highlighted the implications for their children's cancer risk as an important motivating factor.

#### HCP Perspective: Biomarker Testing Is the Standard of Care in Lung Cancer

In contrast to the experiences of some patients, HCPs interviewed in this study pointed to biomarker testing as the standard of care for lung cancer. HCPs agreed that proactive biomarker testing should be a part of the initial diagnosis, in alignment with current guidelines, and said that testing should occur prior to referring patients to medical oncology. A thoracic medical oncologist from an academic setting stated that biomarker test results should be included as a part of the standard pathology report for patients with lung cancer, similar to how biomarkers are handled in breast cancer. The oncologist also noted that tissue biopsies should be performed by an expert to avoid rebiopsy due to insufficient sample

One HCP from an academic center shared that their nurse navigator is critical for ensuring that patients in their practice receive biomarker testing. The nurse navigator identifies patients who have not yet received biomarker testing and ensures that tests are ordered, often using pre-existing samples. The nurse navigator also plays an important role in educating patients about the importance of biomarker testing, the different types of tests and samples, and how the results will inform their treatment plan.



"We're ordering it even before we discuss it with the patients. Any new patients that we see if they don't already have biomarker testing, we are ordering it. Or if they've had limited biomarker testing, we want to complete it with our whole in-house testing program or platform, I should say. That's when we are ordering it. We are also ordering it at disease progression either on chemotherapy, targeted therapy, and now we are ordering it at least *EGFR* alone on all of our early-stage patients. Anyone who has any sort of surgery for early stages is getting biomarker testing."

ONCOLOGY NURSE PRACTITIONER/FACULTY

HCPs recognized their important role in alleviating anxiety associated with waiting on biomarker results. Just like the results of staging and imaging, results of biomarker testing are needed to ensure that the patient receives the right treatment, and HCPs must convey to the patient how important it is to gather all of the necessary information before selecting an appropriate treatment. HCPs agreed that patients respond well to the idea that selecting the correct treatment for your specific cancer in the beginning will lead to a better outcome in the end. Most patients trust the judgment of their physicians as long as they explain their rationale.



"It's really incumbent upon us as doctors and nurses and pharmacists to explain to the patient that we have to act on accurate information in order to make these decisions."

THORACIC MEDICAL ONCOLOGIST

#### Patients May Receive Their Results Electronically or From Their Healthcare Team

Patients shared their experiences with receiving results from biomarker tests conducted on tumor tissue, blood, or pleural effusion samples. Most patients were able to bring copies of their results to the meeting. Some patients had received their report electronically through a patient portal before meeting with their physician. Receiving results through the portal allowed these patients to research their results and prepare their questions in advance.



"I was due for a scan anyway, so I had an appointment with my doctor, and we knew the results would be back by then, so we were going to go over them. But I have a patient portal, and I always go on my own anyway. I never like to wait. I like to have my questions ready beforehand rather than getting news and having to absorb it and then think of questions."

#### PATIENT WITH A LUNGEVITY CONNECTION

Others received the report directly from their oncologist, who discussed the results with them. During this meeting, oncologists discussed any biomarkers identified and how the findings in the report would affect their treatment plan.



"I went to my oncologist, and he just pulled out the report and proceeded to tell me that he had good news and that I had *MET* amplification and that it was targetable. I do have others. He handed me the paper right off the bat, the letter. So, I got that from the first get-go."

PATIENT WITH A LUNGEVITY CONNECTION

In some cases, the oncologist discussed the results of the report without sharing a hard copy, though the report may have been available in the patient portal.

#### HCP Perspective: HCPs Have Challenges of Their Own With Accessing Reports

Discussions with HCPs revealed that they sometimes experience difficulties with accessing biomarker test results reports. According to participants, integration of easily viewable reports into electronic medical records (EMR) systems is desperately needed. Currently all members of the healthcare team may not be able to access the report, especially if the patient did not present to oncology. HCPs shared that reports are sometimes accessible only as downloadable PDFs or as scanned files or faxes, which can make the text illegible. Some HCPs have even changed which tests they order due to lack of legibility of faxed reports. In addition to issues with viewing the reports, even experts struggle with wading through all of the information in difficult-to-read reports that can be as long as 20 pages.



"We'd even had the case where a patient comes in with a seizure into the emergency room. The neurosurgeon takes out a brain metastasis. The consulting physician in the hospital orders the genomics appropriately, but the result gets sent to the neurosurgeon, and nobody looks at it and notices that that patient had an *EGFR* mutation...[The patient] didn't even get a medical oncology appointment for 2 months after their neurosurgery, and they ended up going to hospice, never having had EGFR TKIs. They were sent to radiation, got radiation treatments, all inappropriate management because of these report's getting sent to the wrong people or not being readily available in the chart."

THORACIC MEDICAL ONCOLOGIST

To address these issues, a thoracic medical oncologist suggested that the information from the report should be accessible through the EMR as part of a standard laboratory evaluation, with reflex alerts highlighting actionable results.

#### Both Patients and HCPs Recognize the Importance of Discussing Biomarker Test Results

Discussions between patients and their healthcare team about biomarker test results are an important part of shared decision-making related to lung cancer treatment. These discussions helped patients better understand the results of the report and also provided an important opportunity for HCPs to contextualize the results. The context was particularly important, as both patients and HCPs indicated that "positive" results can provide hope, while "negative" or "indeterminate" results can add to confusion and stress if these results are not accompanied by an explanation in patient-friendly language.



"I was super excited because targeted therapy just came out, and everybody was saying, 'Yay, it's so much easier than chemo.' And it was before we knew about the resistance factor and mutating and progression. So, I was like, 'Yes. If ever I need treatment, I could just go right for this like pill everybody's talking about.' ... So my first thought was, 'I'm so excited.' My second thought was, 'Well, it's not KRAS, so I can't have immunotherapy.' But I was really excited at first to find out I was *EGFR*-positive."

PATIENT WITH A LUNGEVITY CONNECTION

To avoid creating unnecessary anxiety, an HCP suggested setting realistic expectations from the beginning by framing biomarkers as "personalized medicine, state of the art, cutting edge medicine." Although having a biomarker can be framed as a positive outcome, patients should also be made aware that only a subset of patients have these biomarkers. Additionally, it is important to normalize chemotherapy and chemoimmunotherapy to minimize negative feelings from patients who don't have a biomarker. In particular, PD-L1 negativity, therapy resistance, and biomarkers with no associated therapy were noted as results that can be interpreted negatively by patients.



"When I first saw that I was PD-L1 negative, I was relieved. I just said, 'Oh God, at least I don't have to worry about that.' And then it was only subsequently I realized, 'Well, you're missing out on a world of treatments when your PD-L1 is zero."

PATIENT WITH A LUNGEVITY CONNECTION

One of the more difficult issues to navigate in conversations between patients and HCPs is how much information should be discussed. Patients had varying preferences for the level of detail they wanted to receive from their healthcare team. Some patients wanted to know as much information as possible, while others were focused only on next steps.



"I deal better if you talk medical to me and not candy coat things. So, I wanted as much information as possible. The original oncologist that I started out with that was local did not do that. Unfortunately, everything was very much candy coated. I wasn't told that the medication only worked for so long and that the chances of me having a progression again at some point, of course, are unknown, but that was never shared with me."

GENERAL PATIENT

In contrast, a community practice-based provider from a rural area shared that most of the patients in their practice weren't interested in reading the report for themselves. Instead, these patients wanted their provider to distill the information for them. The HCP suggested that a patient-friendly summary would be helpful to guide these conversations. This summary should include information that all patients found valuable about how their biomarkers would affect the treatment plan, such as the types of targeted therapies that may be effective for their cancers and the duration and mode of administration of these therapies. However, another HCP noted that while a patient-friendly summary might be useful, ultimately, the reports are designed for decision-making by the healthcare team. Consequently, the reports must include key information relevant for HCPs, such as a list of the biomarkers evaluated and a description of the technology that was used.

### Biomarker Test Results Can Leave Patients Confused and Concerned

Patients strongly affirmed that even with the support of their healthcare team, the complexity of biomarker testing reports can be daunting. Many patients did not clearly understand exactly which biomarkers had been evaluated by biomarker testing. In addition, they did not know how to interpret indeterminate results or insufficient samples.



"I think for me, I want to see what's normal and what's abnormal. It's like when you do your labs, your routine labs, and they'll say, 'This is the range.' But when you're talking about cancer, they don't... And I don't know about any other diseases, but they don't give you the normal ranges. This is extremely high or you're in the middle. I don't even know if that's possible, but so that you know what it is."

GENERAL PATIENT

Even when the results were clear, patients were confused by mutations that were not actionable and by unexplained and distracting levels of detail.



"I just wanted to know what I had, and telling me what I didn't have is just overwhelming and confusing and just clouds my understanding of what I have."

GENERAL PATIENT

HCPs agreed that the information is often not prioritized in a meaningful way, and important information is often obscured by irrelevant information or legal language.



"For instance, if they're negative for something, *KRAS* negative, they will have a whole section about *KRAS* and all of its implications. So then the patient thinks, ... 'Well, do I have this? There's a whole two pages about this.' But they don't. Yeah, the data gets swamped by all the legal mumbo-jumbo that they put in there. And a lot of just useless words. And now with KRAS-targeted drugs being approved, I think that there's a lack of awareness that they only target G12C and not the other KRAS mutation. So like I was saying, they need to make that distinction."

THORACIC MEDICAL ONCOLOGIST

The medical jargon and highly technical terminology and acronyms used in biomarker test reports were also confusing for patients. One patient found the term "amplification" (referring to an increase in the number of copies of a gene) to be frightening because she misinterpreted it to mean an increase in tumor burden. Patients were unfamiliar with methodology-related terms, like IHC (immunohistochemistry) and FISH (fluorescence in situ hybridization), and with genetic nomenclature.



"I had to figure out on my own that your three top terms, biomarker, molecular and genomic, were all the same thing because the doctors just say stuff. ... I don't know what IHC is, I've never heard of next-generation sequencing, and I still don't know about the PD-L1."

GENERAL PATIENT



"In my report, ...genetic findings, *EGFR* exon 19 deletion, no problem. But then in parentheses, there's an E746\_T751>L, close parentheses. What does that mean? To this day, I have no idea what that in the parentheses mean. And I've not pushed it. I've not gone back to my doctor for details on what's in the parentheses, probably because I am responding to the treatment that I'm on. But still in the back of my head, I know at some point, I may progress, I probably will. So I just wonder if I need to know what that is now."

**GENERAL PATIENT** 

HCPs agreed that reports can create unnecessary worry or send patients down confusing rabbit holes, especially when paired with internet searches using unfamiliar terms. They also commented that there is no meaningful hierarchy of treatments or differentiation between targeted therapies and immunotherapies, which may be confusing for patients who are more familiar with some types of therapy, such as immunotherapy, compared to others.



"It's impossible for a lay person to follow this. It's just not reasonable and not possible. But these reports actually can be misleading because for example, it listed the *EGFR* mutation with links to trials. That's reasonable, but then it also listed for the p53 and the *NFE2L2*. So, a patient will see this and [say], 'Oh, that *NFE2L2* has a catchy name. Why don't I try the clinical trial for that instead of taking osimertinib?' That would be a huge mistake. So really this is more misleading than helpful in this patient."

THORACIC MEDICAL ONCOLOGIST

With respect to clinical trials, HCPs found that they were not always presented clearly in test reports. They emphasized the importance of including clinical trials in addition to FDA-approved therapies, as trials can give patients hope for new therapies on the horizon.



"I think clinical trials should always be considered at every treatment decision. And I tell patients that today's clinical trials are tomorrow's standard of care. They give you access to things that you wouldn't otherwise have access to, but the way it's displayed in these reports is often really bad."

THORACIC MEDICAL ONCOLOGIST



"It gives you all the clinical trial information. Everything's there. I guess it's good to know that as you get more into this whole lung cancer world, you start seeing trials come out for different types that I didn't test positive for at that time. So I think it's good to see [they test for] that and have a little hope that maybe eventually mine will show up."

PATIENT WITH A LUNGEVITY CONNECTION

### Patient-Facing Summaries and Simplified Reports Support Shared Decision-Making

Both patients and HCPs shared recommendations for strategies to help patients better understand their biomarker test reports and support productive discussions with their healthcare teams. In particular, patients were very interested in having an accessible summary of key implications based on their results. They suggested that the summary should be written for a general audience, perhaps at a community college-level, in order to include the necessary information while also making the report accessible to patients. The summary should use clear and consistent language related to testing, as the Consistent Testing Terminology Working Group found that patients reported "inconsistent test terms" as a common barrier impeding effective communication between patients and providers (Consistent Testing Terminology Working Group, 2020). To facilitate these conversations, HCPs recommended highlighting the most pertinent information in patient summaries and clarifying the meaning and implications of not having a biomarker detected. This pertinent information should include the implications of the biomarker test results for therapy and prognosis, as these aspects were of utmost importance to patients.



"Give me the outcome, the diagnosis, prognosis. I want it in plain English. I don't want you to sugarcoat it. I don't want you to use medical terminology and then I have to try and figure it out."

GENERAL PATIENT

Additionally, patients wanted to understand the implications of their results for their family. They wanted to know whether they had been tested for any inherited mutations and whether their children should be tested. Given the importance of this information to patients, inherited mutations that may have familial implications (germline mutations) should not be buried in the middle of a somatic analysis report.



"The first question that I had was 'Do my kids need to be tested? Is this something that I'm going to pass down to my family?' And I wanted to know, 'Was it something that I got from my parents? How do you get it?' They don't exactly know how you get it, but they do know that it is a mutation in the gene of this cell of the cancer. So, it needs to be broken down."

GENERAL PATIENT

Many patients shared that they used the information in their reports as a starting point for additional research to educate themselves about their disease. They searched for relevant internet resources and webinars, support groups, and educational materials from foundations, including LUNGevity. To support patients interested in learning more, biomarker test reports can include glossaries of key terms and clear terminology outlining the genes tested and the biomarkers identified.



"I'm a big researcher and I bring a list of questions to my doctor. And I'm lucky because my doctor sits and answers and discusses with me."

PATIENT WITH A LUNGEVITY CONNECTION



"Well, I wanted to know how the medicine works with the EGFR 19, and I also saw that my PD-L1 was zero, so I wanted to know more about that. But most of what I learned from after the report is either through webinars or joining support groups and things like that and talking with other people that are on a TKI or targeted medicine. So, I didn't learn as much as I know now at the time of the report."

GENERAL PATIENT

In addition to patients, even the experts sometimes struggle with wading through all of the information in the report, leading HCPs to recommend strategies for simplification. For example, an HCP recommended aligning reports with the clinical practice guidelines and including flags to highlight positive results and recommended treatment options. Standardizing terminology across reports and tailoring the content to focus on actionable results could also help to avoid confusion for both HCPs and patients.



"I will say that for some of the folks that are learning because we have trainers, residents and whatever, just thinking about all of the different tests and the different nomenclatures that are used, so that can sometimes be a challenge because they're just using different ways of naming things and referring to things. So between [all of the different assays], there can be some variation with just some of how they're referring to the different biomarkers or mutations that creates confusion communicating."

CLINICAL PHARMACIST

In some cases, including important context in reports can help patients understand if additional testing is needed. This context can be beneficial for guiding conversations with the healthcare team about clarifying when and why waiting is important and how additional test results may lead to better outcomes.



"I remember now the oncologist calling me to tell me my results on my liquid biopsy but to tell me also that they were going to do more testing and to make sure that I was okay waiting. And that's when I was called in, when that second testing came back. And it was identified as an *EGFR* 19 deletion to be able to treat me."

PATIENT WITH A LUNGEVITY CONNECTION



"We're evaluating the patient, too, saying, 'This patient has a very low symptom burden, and they can wait for 3 weeks for the tissue biopsy to come. The results will come back.' or 'Note, we need to get started ASAP. Here's why. And this is what we're going to do."

ONC NP/FACULTY

# SUMMARY

### Aligning Physician Needs and Patient Needs in Biomarker Test Reports

Results of this research suggest that there is substantial overlap between the goals and needs of patients and HCPs with respect to biomarker test reports. Both groups agree that simple, easy-to-access reports with clear terminology and patient-friendly summaries would benefit the lung cancer community. An overview of key needs identified by patients and providers participating in this study is shown below in Figure 1.

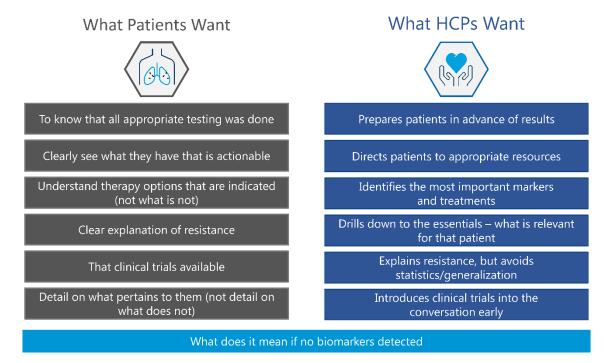


Figure 1. A Summary of Patient and Healthcare Provider-Identified Needs for Biomarker Test Reports

Our goal with this report is to share important context for development of educational resources to support patients and HCPs navigating conversations about biomarker testing. In addition, we hope our results will provide insight for diagnostic laboratories as they continue to refine biomarker test reports for providers, as well as make improvements to improve accessibility for patients. We encourage readers of this white paper to check back with LUNGevity to view new patient resources in development in 2022, including a comprehensive booklet for patients "How to Read Your Biomarker Testing Results Report."

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## REFERENCES

- 1. Chu QS. Targeting non-small cell lung cancer: driver mutation beyond epidermal growth factor and anaplastic lymphoma kinase. *Ther Adv Med Oncol*. 2020;12:1-27.
- 2. Consistent Testing Terminology Working Group. A white paper on the need for consistent terms for testing in precision medicine. https://www.commoncancertestingterms.org/files/Consistent-Testing-Terminology-Whitepaper-070720.pdf. Accessed May 18, 2022.
- 3. König D, Prince SS, Rothschild SI. Targeted therapy in advanced and metastatic non-small cell lung cancer. An update on treatment of the most important actionable oncogenic driver alterations. *Cancers (Basel)*. 2021;13(4):804.
- 4. Martin N, Dropkin L, Redway L, et al. Patient perceptions of biomarker testing: a mixed-methods approach to understand the patient experience related to biomarker testing for NSCLC. *Oncol Issues.* 2022;37(1):58-62.
- 5. Martin NA, Tepper JE, Giri VN, et al. Adopting consensus terms for testing in precision medicine. *JCO Precis Oncol*. 2021;5:1563-67.
- 6. Skoulidis F, Heymach JV. Co-occuring genomic alterations in non-small cell lung cancer biology and therapy. *Nat Rev Cancer*. 2019;19(9):495-509.

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