PATIENT PERCEPTIONS OF BIOMARKER TESTING

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

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In Brief

As precision medicine becomes more common in the management of lung cancer, little is understood about the patient experience with biomarker testing, particularly patients of underserved populations. This study used survey and focus group methodology to determine patient perspectives on the educational needs within this community.

A patient-directed survey was developed by a patient advocacy group collaboration and distributed in April-June 2020. The survey criteria included a diagnosis of non-small cell lung cancer (NSCLC), age of 21 years or older, and United States residency. Two main groups were surveyed and analyzed: a patient group sourced through a general panel of patients and the email database of the Patient Advocate Foundation (a non-profit organization supporting low-income patients), and a group connected to the LUNGevity Foundation, a lung cancer patient advocacy organization. While patients connected to advocacy groups have better awareness and perceptions of biomarker testing, the entire process may need adjustment to improve the patient experience.

Advances in precision medicine using biomarker testing to determine therapy targeted specifically for an individual patient promise to optimize cancer treatment. However, the medical community has concerns around key issues related to increasing use of precision medicine, including potential privacy issues, discrimination (by employers, payers, or other groups), personal safety, limited personal benefit, and patient confusion.[1,2] Additionally, previous research efforts have shown gaps in communication about precision medicine education particularly related to breakdowns in the patient-provider interaction.[3,4] With 20 drugs approved for the treatment of lung cancer with 9 unique biomarkers, such testing has become more common. Therefore, patients are likely to have many questions about the process, including:

- How do I learn more about biomarker testing?
- How is biomarker testing different from other tests and biopsies?
- Who will help me understand the results?
- How are these tests used for treatment planning?

Little research outside of the context of genetic counseling has explored perceptions of communication toward use of precision medicine in patients with cancer. Fewer studies have considered the perspectives of patients themselves. Despite lung cancer treatment being highly biomarker-driven, patients with lung cancer typically do not receive genetic counseling because a clear inheritable component has not been demonstrated. To highlight areas of need for continued education and information for both patients and their treating clinicians, this study explores the patient perceptions of communication and experience with biomarker testing, specifically to better under stand barriers faced in accessing comprehensive testing in diverse patient groups. Alongside the accompanying article focusing on clinician perceptions and use of biomarkers, which will be published in Volume 37, Number 2, *Oncology Issues*, this study attempts to identify the patient perspective related to biomarker testing, with a goal of recommending specific interventions that can be conducted in conjunction with other clinician-directed initiatives to optimize nonbiased guideline-concordant cancer care.

Survey Development

In 2020, LUNGevity developed a comprehensive survey with questions focused on understanding the treatment journey of individuals with advanced-stage NSCLC. The Patient Advocate Foundation also contributed to survey development. Specific questions related to understanding the biomarker testing experience were developed with input from patients with lung cancer and tested with other patients. The survey was semi-structured, with most questions having multiple choice answers or Likert-type questions. Survey data findings were used to create an in-depth focus group guide specifically on understanding barriers to testing and receiving feedback about specific types of interventions to bridge the testing gap. The study protocol was approved by Advarra IRB on April 13, 2020, and the instruments (Appendix A and Appendix B) are available online at accc-cancer.org/eliminating-disparities.

Study Sample and Data Collection

Patient survey recruitment was conducted through three sources: 1) LUNGevity Foundation social media; 2) the Patient Advocate Foundations' email database; and 3) an online national panel of patients. For Patient Advocacy Foundation email recipients and Edge national panel respondents, invitations to complete the survey were distributed by email from April to June 2020 to a random sample of patients with lung cancer. The survey was open to anyone living with a diagnosis of locally advanced or metastatic NSCLC, and 21 years of age or older. Sampling was restricted to the United States.

Survey Analysis

Descriptive statistics were conducted on key items of the patient survey, using Chi-square (X^2) analysis for categorical variables and T-tests for continuous variables to examine differences between the LUNGevity and general patient sample. Analysis between these cohorts was conducted to understand whether a more educated and engaged patient population with a higher socio-economic status encountered the same issues as the general population of patients with NSCLC. Statistical analysis was conducted using SPSS 27 (IBM: Armonk, NY). Values were considered significant when P<.05.

Post-Survey Focus Groups

Following the survey data analysis, a guide for patient focus groups was created to help provide context to ongoing questions about use of biomarker testing. Six patient focus groups representing diverse ages and geographic locations were conducted recruiting from LUNGevity outreach platforms and from a panel sample through Edge Research and had the same eligibility criteria as the survey. Focus groups were conducted using Zoom and recorded. Data were transcribed verbatim and thematic analysis was conducted to identify emergent themes. All focus group transcriptions were coded, and themes were coalesced until saturation was reached.

Sample Demographics

Demographics of the LUNGevity and general patient sample are provided in Table 1 on the ACCC website at accc-cancer.org/eliminating-disparities. A total of 248 total patients were included for analysis. The two samples were similar in age and race, but differed in gender ratio, type of NSCLC, insurance status, income, and treatment status. The LUNGevity sample cohort was predominantly female patients with adenocarcinoma with higher socioeconomic status, and the general population reflected patients from more diverse ethnic and racial backgrounds, lower income levels, and low-to-no insurance coverage.

Characteristics of Biomarker Testing

When first learning about biomarker testing, 66 percent of the LUNGevity patient group report having their doctor raise the topic, compared to 40 percent of patients in the general population (P<.01). In terms of patient-reported testing rates, 85 percent of the LUNGevity cohort report having biomarker testing conducted compared to just 52 percent of the general sample. Of the patients who indicated that they have had biomarker testing conducted, 78 percent of the LUNGevity cohort and 54 percent of the general patient sample (P<.01) only had to see one doctor before receiving biomarker testing (Table 2, at accc-cancer.org/eliminating-disparities). The LUNGevity sample is more likely than the general population group to have multiple mutations tested at a single time (55 percent vs. 31 percent P<.01) rather than testing for only the most common mutations (23 percent vs. 41 percent), a guideline-concordant means of testing. Despite being more likely to have multiple mutations tested at once, which typically delays receipt of results for the more thorough comprehensive testing, 46 percent of LUNGevity patients report receiving their results within 14 days of testing compared to 34 percent for the general population (P=.12).

In the focus groups with LUNGevity patients, awareness of the term "biomarker testing" has permeated, compared to varying degrees of awareness and understanding of the term among patients in the general population. Focus groups with general patients revealed a lack of knowledge of what the term means, and for those who may have heard the term, there was some confusion of biomarker testing with genetic testing for inherited mutations. Some patients had a good awareness of the link between biomarker testing and precision medicine, but this was more common for patients in the LUNGevity cohort compared to the general population.

"I heard of it. Don't know too much about it, just heard of it as far as the name. [It was] *not discussed with me."*
Black Patient

"[It is] *custom medicine. They take your tissue or blood, trying to look for these mutations to get your specific cancer under wraps. It's really precision medicine. Customized to your specific cancer and can avoid chemo."*
Younger, Urban Patient

Further, focus group patients indicated that they did not always know when biomarker testing was conducted as it blends in with other appointments and tests. The most knowledgeable patients were those who had recurrence and were tested or re-tested and the least knowledgeable patients were those whose first-line treatment worked and have not had a recurrence.

"[I heard about it] *during the first biopsy, my report had EKG, etc., and know from reading that they can treat you with targeted therapies. I didn't know that they were doing it."*
Patient from Rural Area/Small Town

Comprehension of Biomarker Testing Results

Most patients report being informed of the results of their testing: 93 percent of the LUNGevity group and 76 percent of the general patient sample (P < .01) (Table 3, at accc-cancer.org/eliminating-disparities). A similar percentage indicated that having access to a copy of the testing results is important to them. However, roughly half of patients reported not having their results shared with them; less than a quarter of patients in both groups received a printed copy.

In the LUNGevity group, 84 percent report that their doctor explained the results of their biomarker testing to them. Just over half (55 percent) of the general patient population indicated that their doctor explained the results to them (P< .01); 21 percent reported that another healthcare professional explained the results of the testing. LUNGevity patients are more likely than the general patient sample to report that their oncologist referenced their biomarker testing results (91 percent vs. 55 percent, P < .01). Patients in both groups did not indicate that many other healthcare professionals referenced their results during an appointment.

Even though more patients in the LUNGevity panel indicated that their doctor explained the results of testing and their oncologist referenced testing in their appointments, only 65 percent indicated that they understood the terms included in the testing results, not much higher than the 56 percent of the general patient population (P = .24). Despite this, biomarker testing provides benefits to patients. Nearly all patients reported that biomarker testing gave them confidence that the care team was doing everything possible to treat their specific lung cancer type and they (patients) understood how this information would be used to make decisions about their treatment. Most patients also believed that they made better decisions about their own care based on the results of the biomarker testing.

Focus group participants confirmed the survey data. They indicated that the oncologists were the main conduit to both learning about biomarker testings, as well as to understanding the results of that testing. However, trust and connection with the oncologist varied. Younger and older urban patients in the focus groups had the best connection with the oncologist, while rural, low-income, and patients of color reported not getting as much time with the oncologist as they would like.

"The doctors see 10 patients a day. Each of us have different kinds of cancers…The person most likely to talk to you about biomarker testing is the person you spend the most time with and that's in your treatment center. I spend 30 minutes with doctors. I spend 6 hours with the nurses in the immunotherapy treatment."
Low Income Patient

"The pulmonologist never mentioned biomarkers. I have to think if anyone knew, it was my oncologist who changed my chemo cocktail. I also had a radiation oncologist, but he didn't do bloodwork, strictly scans. I assume my oncologist knew what my biomarker was. I would be interested to go back and ask him about that."
Low Income Patient

Concluding Thoughts

The survey reveals a significant divide in access to testing and incidence of biomarker testing being discussed with healthcare providers between LUNGevity-connected patients and those in the general patient population. Patients associated with an advocacy group appear much more likely to learn about and pursue biomarker testing without having to see multiple providers to access the technology, while patients with low socio-economic status are less likely to report having received biomarker testing. Generally, focus group participants reported a huge variation in how they were treated (in terms of communications and empowerment with decisions) by their healthcare team. Lower-income and patients of color were more likely to describe unsatisfactory experiences.

The data presented here show just over half of patients with NSCLC undergo some form of biomarker testing. While the majority who are tested are informed of their results and get

some explanation, 27 percent of those in the general patient population do not know their results. A primary concern for patients is that while the majority believe it is important to have access to their testing results, fewer actually receive a copy.

Oncologists are the primary source of testing information and discussion of results, suggesting a significant opportunity to educate and encourage other members of the cancer care team on biomarker testing and how to communicate about it. For patients, it makes sense for the oncologist to be the "source of truth" for diagnosis and treatment plans, but the relationship, time spent, and trust level is mixed and some patients, especially those of color, say the oncologist is not always on top of their care. There may be a role here for education on interpreting and explaining biomarker testing for other advanced healthcare providers, such as oncology nurse practitioners, physician assistants, and pharmacists. As mentioned in a focus group, patients may have limited time with the oncologists but could spend hours with other oncology staff members.

The study has limitations. The online distribution of the survey may have excluded patients with limited internet access. Furthermore, patient survey opinions were reported with descriptive statistics only, which limits the generalization to the complete population of patients with NSCLC.

In summary, this study shows potential missed opportunities for patient education as patients believe that biomarker testing benefits them even though all their questions are generally not answered prior to testing. There may be a disconnect between oncologists and patients on how test results should be communicated and perhaps the ideal biomarker-testing journey should be more patient-centric (Figure 1, following page). Patients prefer to hear about their biomarker testing from their oncologist. Patients are less interested in the specifics of the biomarkers but want to know what it means for their treatment approach and potential side effects of that treatment. Patients want a tangible take-away, written in clear language and supported with visuals that explains key points of discussion with their doctor. Such a tool would be useful for the provider as well to ensure consistent, comprehensive communication with each patient. Additional links and reference information for patients to continue to read on their own time would be appreciated. Lastly, time to process the information and follow-up visits to discuss any additional questions are important to feel secure with their understanding of testing results.

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The Tables referenced throughout this article can be found on the ACCC website at accc-cancer.org/eliminating-disparities.

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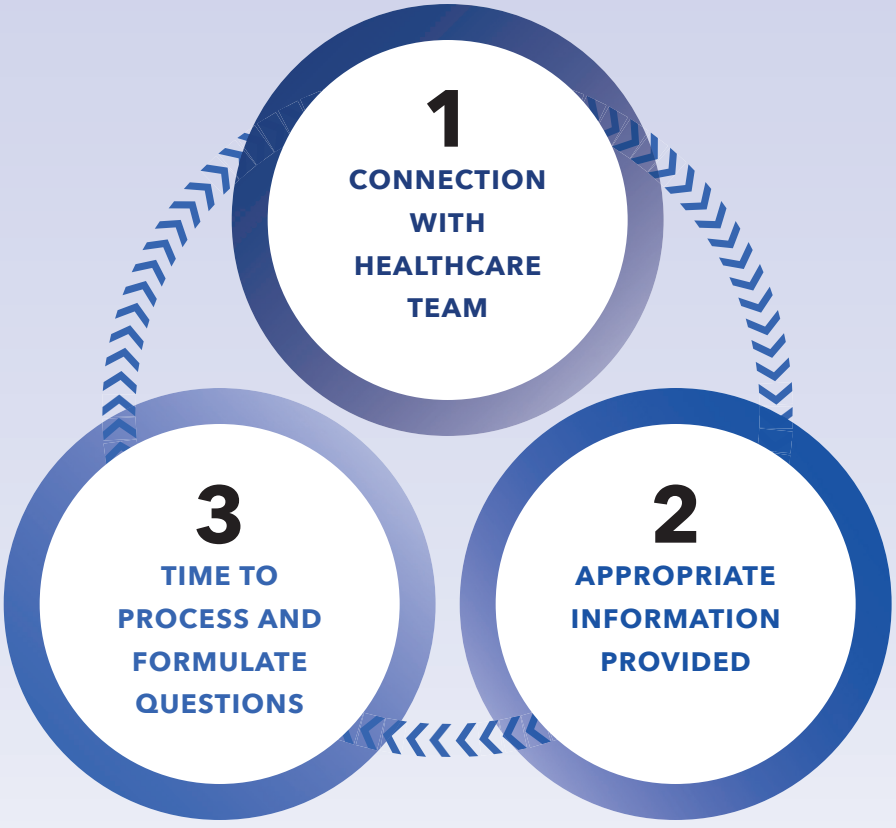
FIGURE 1. The Desired Biomarker Testing Experience, from the Patient Perspective*



1. Connection with healthcare team: Patients want to hear from the oncologist directly or someone from the oncology team, such as the oncology nurse practitioner. Patients are also open to hearing from a biomarker specialist. From these discussions, patients want to know more about treatment and side effects and are less concerned with the "alphabet" of biomarkers.

2. Appropriate information provided: Following a discussion with the oncologist, patients want information when there is an action to take, such as written information with visuals (but not images of cancer tissue).

3. Time to process and formulate questions: Patients want at least a day to review the materials and think about the questions they have for the oncology team prior to meeting again. Biomarker testing results need to be easily accessed for patient review.

A publication from the ACCC education program, "Eliminating Precision Medicine Disparities." Learn more at accc-cancer.org/eliminating-disparities or scan this QR code.

The Association of Community Cancer Centers (ACCC) is the leading education and advocacy organization for the cancer care community. For more information, visit accc-cancer.org.

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