

Patient Insights as the Foundation for Value

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RESEARCH QUESTION

How do metastatic NSCLC patients' perspectives and experiences shape cancer-related treatment decision-making?

KEY TAKEAWAYS

- For value assessment to accurately reflect patient realities, better insights into what determines value for patients is needed
- To inform development of a new open-source model in non-small cell lung cancer (NSCLC), IVI conducted research with patients about what determines value
- NSCLC patients highlighted the importance of personalized care, affordability, side effects, and mode of administration as key determinants of value
- IVI's NSCLC value model takes initial steps toward incorporating the dimensions identified by patients, but broader efforts to include patient perspectives are needed in value assessment

IMPORTANCE OF PATIENT PERSPECTIVES

Oncology is an area of immense clinical need and a primary driver of healthcare spending, making it a prime target for assessment of the value of available medical interventions. Of the many forms of cancer, lung cancer is the leading cause of cancer-related deaths worldwide. The American Cancer Society estimates that of the more than 1.7 million new cancer cases in the U.S. in 2018, 13.5% are lung cancer.ⁱ Non-small cell lung cancer (NSCLC) accounts for an estimated 85% of lung cancer cases and comprises adenocarcinoma, squamous cell carcinoma, and large cell carcinoma.ⁱⁱ

ⁱInclusion criteria for the study: Individual diagnosed with de novo or recurrent stage IV NSCLC, Age ≥18 years, and fluent in English.

ⁱⁱStudy protocol and discussion guides were reviewed and approved by Advarra Institutional Review Board (Columbia, MD).

There is increasing recognition that currently available clinical evidence does not adequately represent patient heterogeneity, and that current methods for value assessment cannot yet systematically include patient value factors. To move toward this needed advancement in methods requires that we first understand what drives value for patients confronting this disease.^{iii,iv,v} IVI partnered with research experts at LUNGeity, a patient organization, and EGFR Resisters, a grassroots patient group, to explore factors that patients consider when making value determinations and decisions about available treatment options for NSCLC.

METHODS

IVI conducted structured in-depth interviews and focus groups with metastatic NSCLC (mNSCLC) patients to investigate patient perspectives on disease burden, experiences with treatment, and the impact of cancer therapy on patients' lives and treatment decision-making.

Eligible participants¹ residing in two large metropolitan regions were invited by email and screened by telephone to confirm eligibility by Schlesinger Group, a market research firm.

Semi-structured discussion guides were designed to elicit thoughts, opinions, and experiences about cancer care and treatment, as well as reports of the factors most important to patients when considering treatment options and sources of perceived value in treatment for mNSCLC. Contributions by research experts at LUNGeity and patients associated with EGFR Resisters, two patient organizations, were instrumental in validating the guides.²

Discussions held in June and July 2018 were audio-recorded and transcribed verbatim. Researchers used thematic analysis to identify salient themes and factors that patients with mNSCLC consider meaningful when making treatment decisions; and the degree of concordance between patients on the issues identified. IVI published a technical paper summarizing the findings.^{vi}

FINDINGS

Several broad themes characterizing patients' experiences with care were identified through in-depth discussions with mNSCLC patients. Patients emphasized the need to make frequent trade-offs in treatment decisions, for example in weighing treatments' potential efficacy against impacts on quality of life and day-to-day functioning. Patients also highlighted the urgency created by the metastatic nature of

their diseases, with a high degree of importance placed on rapid access to information on their treatment response and ability to switch therapies quickly when not responding.

Participants also identified specific determinants of value in their treatment experience (Figure 1), including:

- **Care personalized to individual needs and goals that was also coordinated and comprehensive.** Patients sought out treatment facilities that could offer a wide range of services from genetic testing to insurance assistance to mental health support.
- **Treatments and care that were affordable throughout their treatment journey.** For many participants, value in care equated to affordability and treatments that were covered by their insurance with low out-of-pocket costs. Access to clinical trials and financial assistance programs were also considered key components of financial value, as they were stopgaps when treatments were not covered.
- **Treatments that offered tolerable side effect profiles.** These elements of value were associated with a preserved quality of life, which has become feasible with targeted treatments. For many participants, the “feeling” of cancer only manifested itself through treatment side effects. Among participants who experienced significant side effects, they were forced to make tradeoffs between continuing treatment or switching to something that may be more tolerable but potentially less efficacious.
- **Treatments that offered convenient route of treatment administration.** This included ease and convenience, mechanism/mode of administration (e.g. oral vs. intravenous), ease of obtaining the medication if self-administered, and ability to adhere to therapy. Treatments that were self-administered and offered convenience further allowed participants to maintain the activities of their daily lives.

IMPORTANCE AND RELEVANCE

The concerns and preferences described by mNSCLC patients reflect patient perspectives common to many other chronic and high-morbidity, high-mortality diseases. To ensure such patients receive optimal, high-value care, such factors must be incorporated into value assessment models, as opposed to merely mentioned as narrative context.

IVI used this patient-focused research to inform the patient value factors incorporated into the recently released IVI-NSCLC model.³ For example, model parameter settings allow the user to adjust costs to match the costs to patients, and the multi-criteria decision analysis (MCDA) tool includes both mode of administration and the risk of 10 distinct side effects as attributes that can be weighted according to how important those aspects are to the decision-maker.⁴

“ Well, I think quality of life ties in to the side effects and the dosing, right? So, it's a better quality of life if you can take the medication at home and not have to go into an infusion center. So, there's a pro in terms of the dosing choice, but it's also a quality of life issue because you don't have to travel. You don't have to drive. So, a lot of those things kind of have a double or triple benefit in a way. It's also more safe and tolerable. So, quality of life ties into that in terms of you don't feel so sick all the time. ”

- mNSCLC patient

FIGURE 1. Factors Identified by mNSCLC Patients as Affecting Value

- Treatment efficacy
- Duration of progression free survival
- Duration of overall survival
- Mode, frequency, and geographic location of treatment administration
- Risk of side effects, severity of side effects, availability of therapies to manage side effects
- Functional ability (physical, mental, social), productivity, absence/presence of treatment fatigue
- Provider awareness of treatment options
- Patient and provider communication
- Care coordination
- Wrap-around care
- Personalized care
- Out of pocket costs
- Insurance coverage
- Availability of additional financial assistance
- Eligibility for clinical trial participation
- Mutation status and eligibility for targeted therapies
- Hope

“ I think it really has to start with an open dialogue, and I think the doctor and the patient need to decide up front what are your long-term goals. Do you want something that's the most aggressive treatment, that might give you side effects, but you want to prolong your life or hopefully get a really good response? Or do you want something that's not going to be as aggressive? You won't live as long, but you have a better quality of life. And I think that that's where that balance has to be decided and then from there, you can go on and make good treatment decisions. ”

- mNSCLC patient

³IVI's first oncology-specific [Open-Source Value Platform \(OSVP\)](#) model focuses on NSCLC. Specifically, the IVI-NSCLC model examines the value of sequential treatment strategies for patients with epidermal growth factor receptor positive (EGFR+) NSCLC.

⁴For full details or to access the IVI-NSCLC model, visit <https://www.thevalueinitiative.org/ivi-nsclc-value-model/>.

CONCLUSIONS

Studies such as these are important to defining the heterogeneity of patient experience, as well as the factors and relative importance of patient preferences in care, including weighting of risks and benefits and defining preferences that affect both clinical and quality-of-life outcomes. Value assessment has not achieved the ability to represent patient factors of value in methods-based calculations because such factors are not captured in clinical evidence.

Perhaps most important, such research offers a call to action for further investigation. For example, research is needed among less advantaged populations – due to race/ethnicity, acculturation, language proficiency, socioeconomic status, access to care, or insurance status – to identify additional factors related to mNSCLC treatment that define value. In addition, further research is needed on the impact of genetic testing in optimizing treatment sequences and how patient preferences can inform clinical pathway development for populations with genetic mutations in NSCLC.

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ABOUT THE INNOVATION AND VALUE INITIATIVE

IVI is a nonprofit organization committed to advancing the science and improving the practice of value assessment in healthcare through collaboration among thought leaders in academia, patient organizations, payers, life science firms, providers, delivery systems and other organizations.

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¹American Cancer Society. Cancer Statistics Center: 2019 Estimates. 2019. Available at: https://cancerstatisticscenter.cancer.org/?ga=2.193423983.310206083.1534789562-217160984.1533672952#. Accessed May 15, 2019.

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⁴Perfetto EM, Oehrlein EM, Boutin M, Reid S, Gascho E. Value to Whom? The Patient Voice in the Value Discussion. *Value in Health*. 2017;20(2):286-291.

⁵FasterCures—A Center of the Millken Institute, Avalere Health. Patient-Perspective Value Framework (PPVF) Version 1.0. May 2017. Available from: <http://www.fastercures.org/assets/Uploads/PPVF-Version-1.0-Methodology-Report-Final.pdf>. Accessed May 15, 2019.

⁶May-Slater S, Huber C, Silverstein A. Patient Perspectives on Value in the Treatment of Non-Small Cell Lung Cancer. November 2018. Available from: https://www.thevalueinitiative.org/wp-content/uploads/2018/11/IVI.126_Technical-Report_FINAL.pdf. Accessed May 15, 2019.