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BIOMARKER TESTING IN NSCLC: INSIGHTS FROM PATIENTS AND CAREGIVERS

Clinical background:

Biomarker testing, essential for guiding treatment in non-small cell lung cancer (NSCLC), is widely performed at diagnosis, but delays in obtaining results, variation in testing practices, and inconsistent communication may serve to limit its clinical impact.

Document purpose:

The aim of this blueprint is to define the level of awareness and understanding of the precision oncology and biomarker testing landscape among patients with NSCLC and their caregivers, and to determine the areas where patients and caregivers require additional education/support from health-care professionals to improve the shared decision-making process.

Introduction:

Lung cancer remains one of the most common and deadly cancers worldwide.[1] It is often diagnosed at advanced stages, which can necessitate complex, multimodal treatment approaches.[2,3] Advances in biomarkers, targeted therapies, and immuno-oncology, often guided by biomarker testing, have transformed care in NSCLC, improving outcomes.[4] However, despite the critical role of biomarker testing, its use remains inconsistent,[5,6] and global variability in biomarker testing timelines, communication, and understanding may hinder informed decision-making in NSCLC.

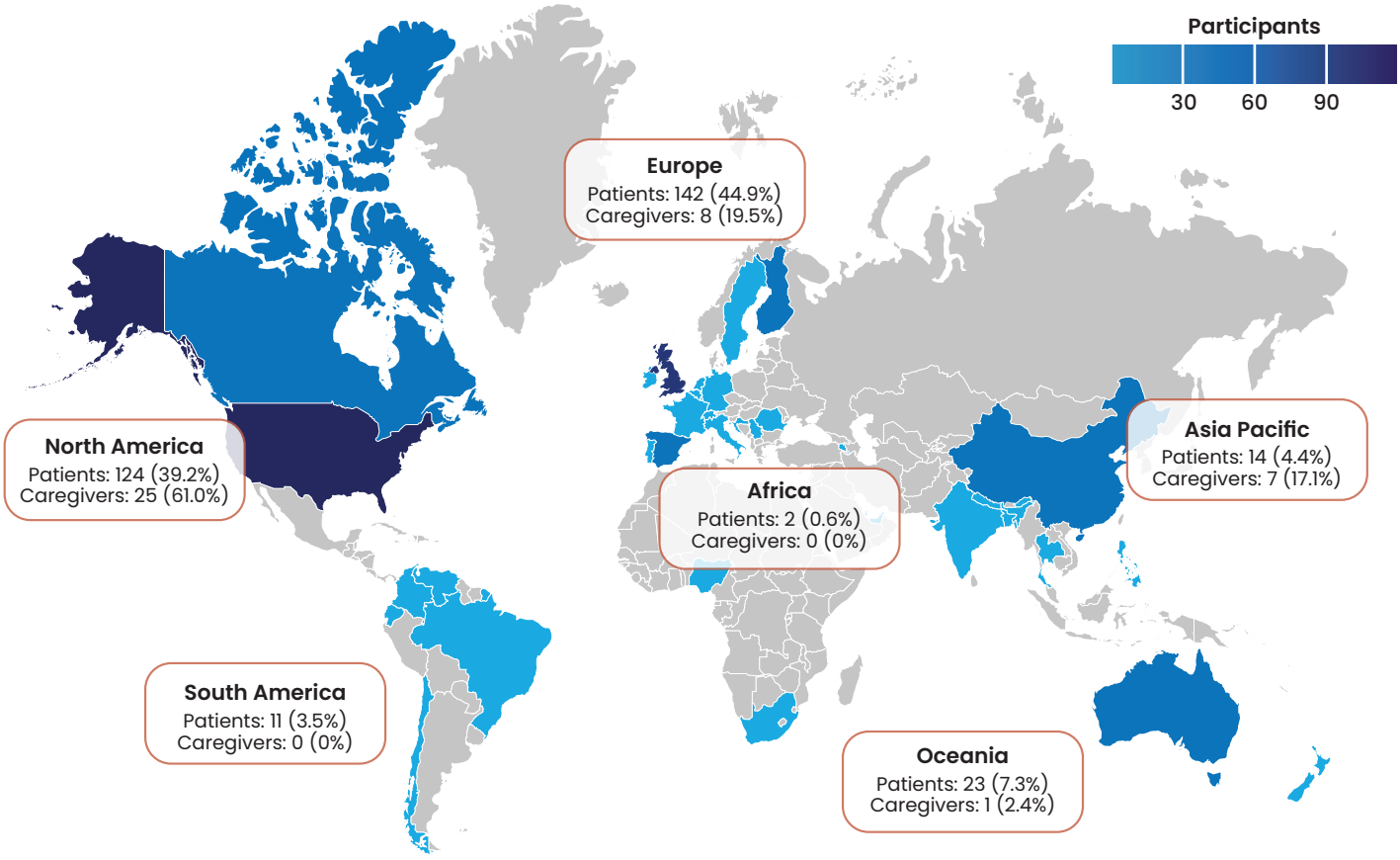
Methodology:

A global, cross-sectional online survey of 316 individuals diagnosed with NSCLC within the previous five years ('Patients') and 41 caregivers to individuals with NSCLC ('Caregivers') from 37 countries (Figure 1) was conducted to evaluate international experiences and perceptions of biomarker testing in NSCLC and assess awareness, knowledge, and attitudes surrounding biomarker testing. It sought to obtain an up-to-date understanding of the gaps that should be addressed to truly support shared decision-making.

Survey awareness was generated through newsletters and social media campaigns conducted using Facebook, X (formerly Twitter), and LinkedIn, in collaboration with various International Societies and patient support groups including (but not limited to) the International Association for the Study of Lung Cancer (IASLC), the International Society of Liquid Biopsy (ISLB), LUNGevity, Lung Cancer Europe (LuCE), The Israeli Lung Cancer Foundation (ILCF), EGFR Resisters, and NTRKers. The survey was also shared by the steering committee across their clinical networks. The survey was open for completion between January and April of 2024 and was available in five different languages (English, French, Portuguese, Spanish, and Traditional Chinese).

Questionnaires were conducted online using the Qualtrics platform and covered respondent demographics, a range of topics across the diagnostic and treatment journey including history of biomarker testing, related communication and education, self-perceived familiarity, and informational needs, and outcome of treatment approaches.

Figure 1. Geographical distribution of survey respondents



KEY SURVEY FINDINGS

Respondent demographics

In total, 357 respondents from 37 countries completed the survey (316 patients; 41 caregivers). The majority of respondents were from North America and Europe (North America: 39.2% of patients, 61% of caregivers; Europe: 44.9% of patients, 19.5% of caregivers; see Figure 1 for the complete data set). The majority of participants were female (76.3% of patients, 75.6% of caregivers) with a high level of education (63.9% of patients, 80.5% of caregivers having had a tertiary education). Many respondents (75.6% of patients, 51.2% of caregivers) were actively involved in advocacy groups.

Disease characteristics

Among patients (n = 316), 67.7% of those with a diagnosis of NSCLC had advanced disease, 17.1% localised disease, and 13.6% locally advanced disease. Most (84.5%) were currently receiving treatment, 41.5% had stable disease, 15.5% were in remission, 13.0% had disease progression, 5.1% had recurrence, and 2.2% were newly diagnosed (multiple responses were allowed); 72.8% were receiving received care at an academic centre (defined as an academic centre/large city-based medical centre and national cancer centre).

Biomarker testing patterns: disease stage, sample type and testing

Among patients who provided samples for biomarker analysis (n = 278/316; 88% of the total survey population of patients with NSCLC), 97.8% were biomarker-tested at diagnosis, with 15% being tested at progression and 5.8% at recurrence.

At diagnosis, 84.5% reported having a tumour biopsy, 32.4% a liquid biopsy, and 14.0% a cytology sample collected for biomarker testing. At progression, tumour and liquid biopsy rates were similar (60.5% vs 67.4%, respectively), with only 7.0% tested via cytology. At recurrence, tumour biopsy was more common than liquid biopsy (68.8% vs 56.3%), with 12.5% tested via cytology at this stage.

Regional and centre-level trends showed greater liquid biopsy use at progression in both Europe and North America (73.4% and 77.3% respectively), and in non-academic sites vs academic sites (66.7% vs 67.7%, respectively), but small sample sizes in this setting limit comparisons.

At diagnosis, more than 60% of patients (in total and by centre type) had samples taken from the primary cancer site, 20.6% from the site of metastasis, and 11.4% from both. Sampling was less frequent at progression and recurrence, though more often from metastases.

At diagnosis, 50.4% of patients underwent biomarker testing by next-generation sequencing (NGS; testing for multiple biomarkers), 5.9% single assay testing (testing for a single biomarker), and 11.4% immunotherapy testing, such as for PD-L1 (patient-reported data based on the question 'what type of biomarker test did your physician request', with specific mention of NGS), with the remaining patients responding either 'other' or 'I don't know'.

Patients in North America reported the highest use of NGS (65.0%), with a lower proportion in Europe and other regions (39.8% and 37.8%, respectively). The overall proportion of those reporting that their sample had been tested by NGS at diagnosis was higher for people treated at academic centres (56.9%) compared to non-academic centres (41.4%).

Results of biomarker testing: availability, format of delivery

Among patients who underwent biomarker testing, 27.3% of received results within 2–3 weeks, while 24.8% indicated that it took more than 4 weeks. Results were available at the time of diagnosis for just 4.7% and within the same week for 6.5%.

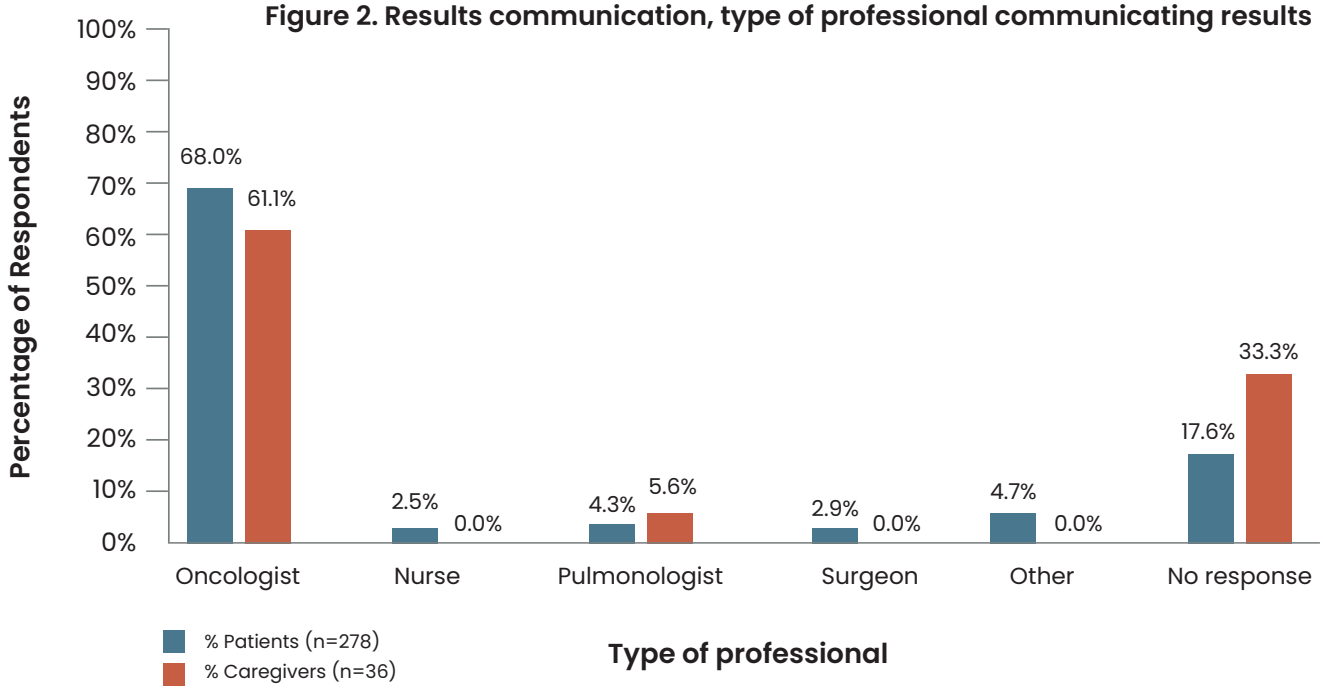
More respondents received results from an oncologist than any other type of healthcare professional (68.0% of patients, 61.1% of caregivers) (Figure 2).

Overall, biomarker testing results were most commonly received by verbal communication (82.4% of patients, 66.7% of caregivers) or by written report (34.5% of patients, 41.7% of caregivers).

Among patients in North America who underwent biomarker testing, 50.4% (vs 42.5% from other regions and just 16% in Europe) indicated that results were provided in the form of a written report. More patients reported receiving written copies of their results when treated in academic centres (38.8% vs 22.2% in non-academic centres), and, specifically receiving them from their medical team (most commonly, from their oncologist), which may also explain why more of them reported a higher level of satisfaction with the information received in this setting, as well as a greater reported understanding of the purpose of biomarker testing.

Overall, more than 80% of respondents received an explanation of their testing; around 45.0% understood

Figure 2. Results communication, type of professional communicating results



most of the information provided (45.3% of patients and 41.7% of caregivers), while 27.8% of caregivers and 16–22% of patients understood all (varied by region).

Dissatisfaction with information received was reported by just 15.1% of patients, with the proportion being lower in academic vs non-academic centres (11.2% vs 26.4%).

Results of biomarker testing on treatment initiation

In terms of the influence of biomarker testing on treatment initiation, 23.0% of patients (the highest proportion in the group of 278 patient-respondents) reported a delay to treatment initiation of more than four weeks from the date of biomarker testing, with similar numbers reporting treatment initiation at 1 to 2, or 2 to 3 weeks post-testing (19.8% and 18.7%, respectively); 28.1% reported starting their treatment before biomarker results were made available.

Among those patients who waited for biomarker results before treatment (group size: n = 196), only 2.6% said it was their own decision (vs 40.9% of caregivers), with most (66.8%) reporting physician recommendation as the reason for delayed treatment initiation; this was consistent across regions and centres.

Overall, most respondents (94.4% of patients and 95.5% of caregivers) indicated that the biomarker testing results were used to guide the choice of treatment.

Attitudes and knowledge of biomarker testing results among survey respondents

More than half of all respondents (60.4% of patients and 50.0% of caregivers; biomarker-tested group: n = 278) sought additional information surrounding the role and possible impact of biomarker testing on their treatment decisions. This additional information was sought mainly from medical teams (72.7% of patients, 80.6% of caregivers), patient groups (61.9% of patients, 50.0% of caregivers), internet/social media (60.8% of patients, 61.1% of caregivers), or other people with lung cancer (44.6% of patients, 52.8% of caregivers) (Figure 3).

Few respondents used medical societies (9.0% of patients, 11.1% of caregivers), other sources (7.9% of patients, 13.9% of caregivers) or traditional media (TV, radio; 3.2% of patients, 2.8% of caregivers). Trends were similar for all groups examined, with the primary source of information being the medical team (Figure 3).

Figure 3. Perceptions regarding biomarker-based decision making and approach to results communication, according to patients and by caregivers

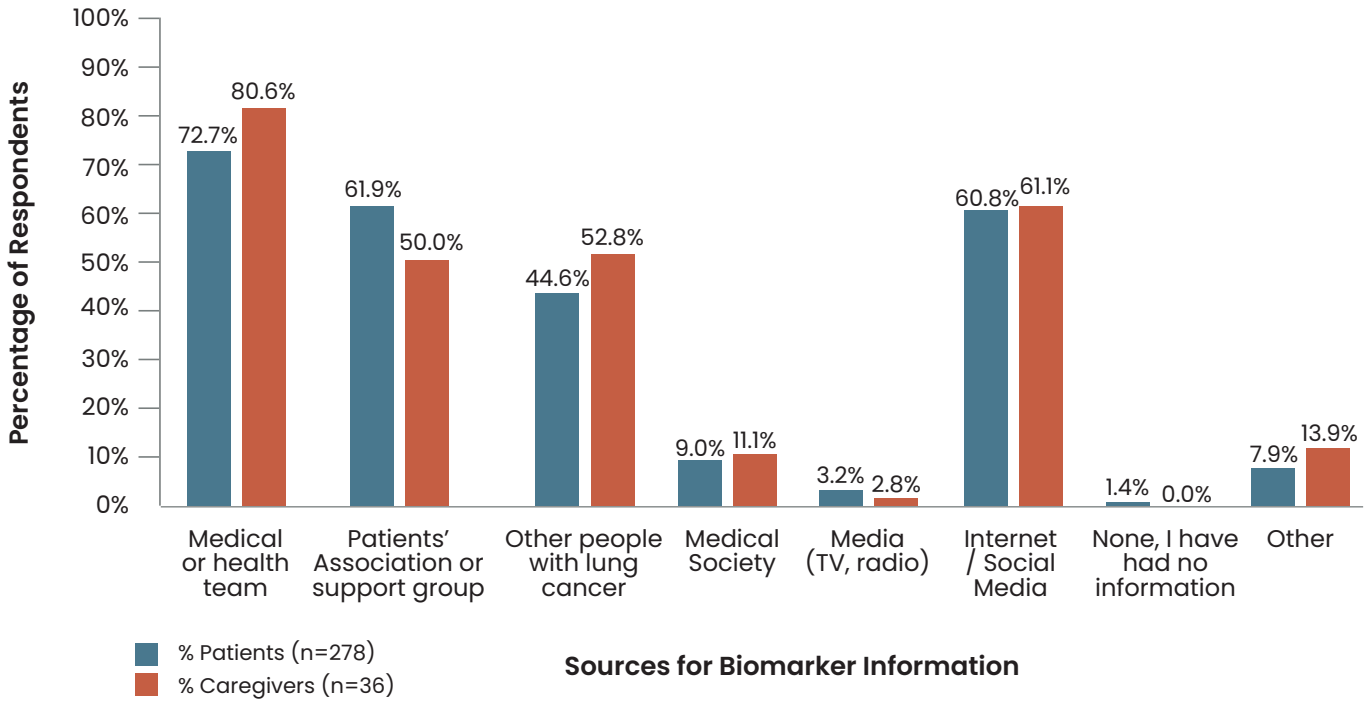
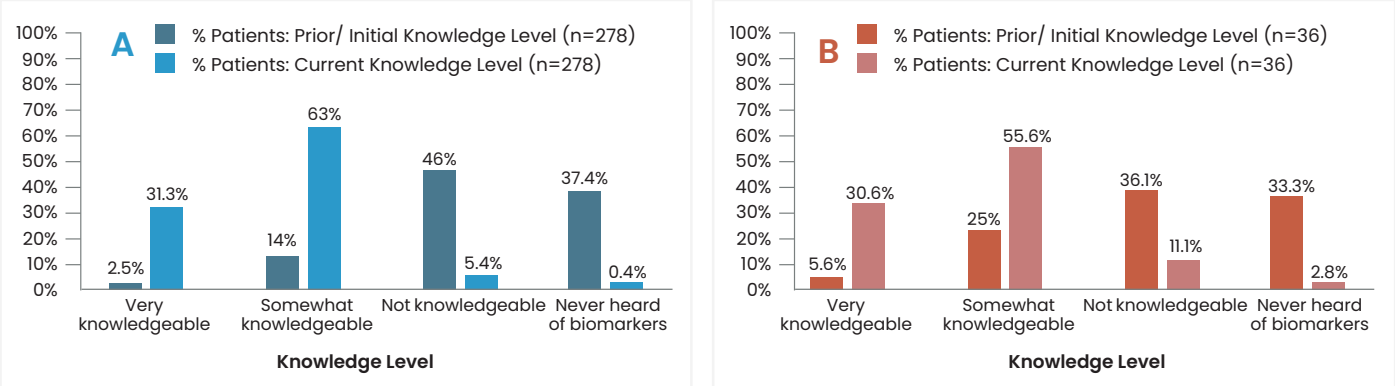


Figure 4. Perceptions of knowledge shift before and after biomarker testing by patients and caregivers

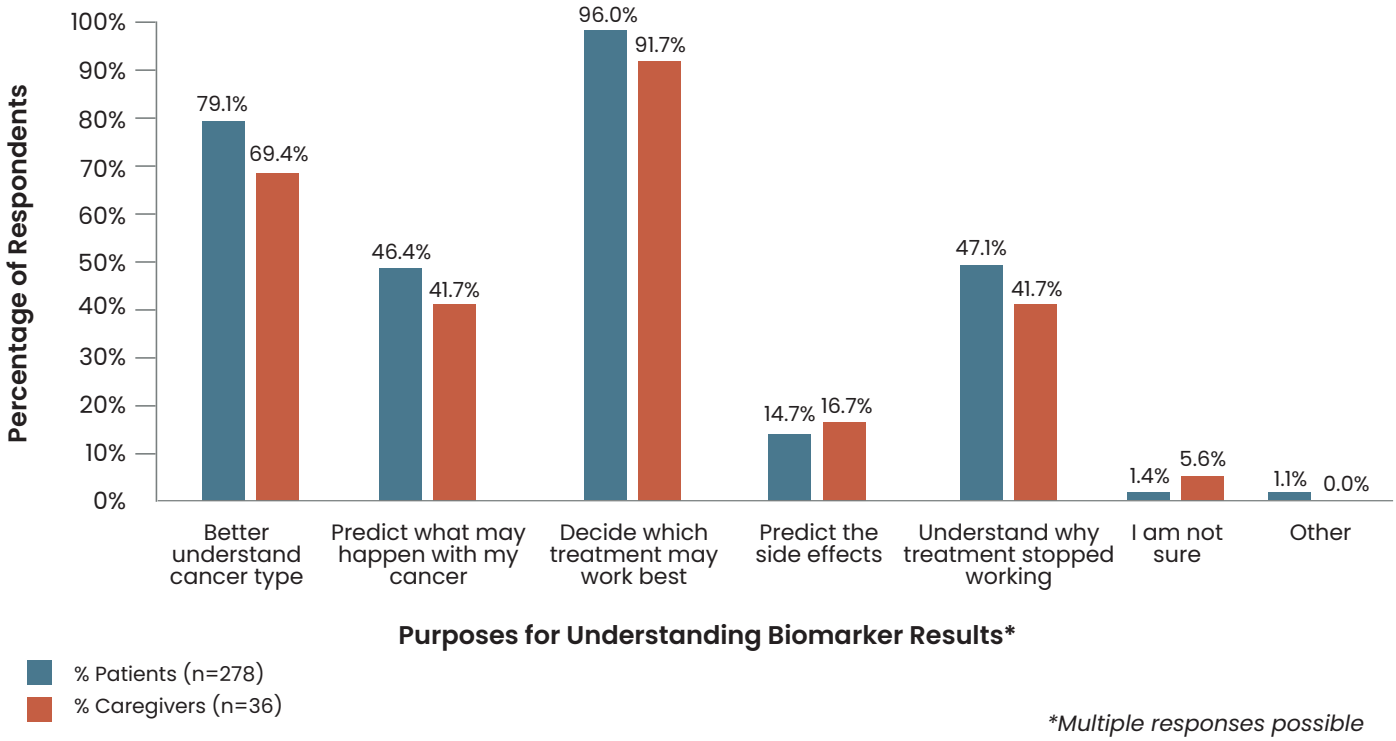


(A) Patient's prior/initial knowledge level versus current knowledge level,
(B) Caregiver's prior/initial knowledge level versus current knowledge level.

Among those patients who underwent biomarker testing, knowledge of biomarkers increased considerably after testing: the proportion reporting that they considered themselves to be 'very knowledgeable' rose from 2.5% to 31.3% and 'somewhat knowledgeable' from 14.0% to 63.0% (Figure 4A).

Among caregivers caring for a friend/family member with NSCLC who underwent biomarker testing (group size: n = 36), 'very knowledgeable' increased from 5.6% to 30.6% and 'somewhat knowledgeable' from 25.0% to 55.6% (Figure 4B).

Figure 5. Patient and caregiver attitudes and understanding of biomarker testing, purposes for understanding biomarker results and information search outcome



*Multiple responses possible

Patient and caregiver attitudes and understanding of biomarker testing among survey respondents

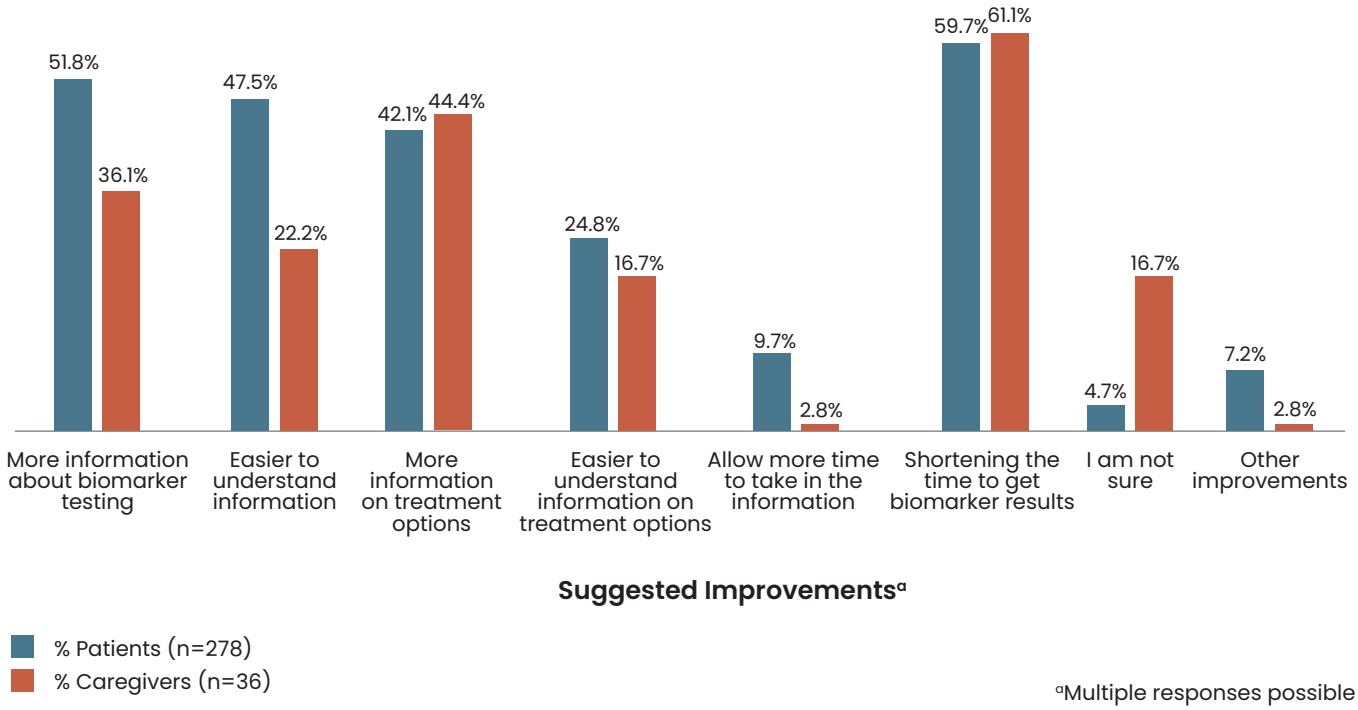
In terms of the perception of 'value' surrounding biomarker testing, a majority of respondents placed a high importance on biomarker testing.

Among patients who underwent biomarker testing, 82.7% and 13.1%, respectively, indicated that they considered biomarker testing to be 'Extremely important' or 'Very important'; among caregivers, values were 86.1% and 11.1% . The highest proportion of patients indicating 'Extremely important' was in North America (92.4%), with Europe and other at regions around 75%.

Among patients who underwent biomarker testing (Figure 5), most cited the purpose of biomarker testing as 'to decide which treatment may work best' (96.0%) and 'to better understand the type of cancer (79.1%); 46.4% and 47.1%, respectively, indicated that they had undergone biomarker testing 'to predict what may happen with my cancer' or 'to understand why a treatment stopped working', while fewer chose 'to predict the side effects' (14.7%). Just 1.4% of patients who underwent biomarker testing were unsure of the purpose.

When asked about the scope for improvement surrounding the process of biomarker testing (Figure 6), patients who underwent biomarker testing indicated that desirable improvements would include shorter time to obtain results of biomarker testing (59.7%), more information about biomarker testing (51.8%), and easier to understand information both overall and as it is relates to treatment options (47.5% and 42.1%, respectively). Caregivers emphasised the need for shorter time to obtain results (61.1%), more information on treatment options (44.4%), more information about biomarker testing (36.1%), easier to understand information (22.2%), and clearer information overall (22.2%).

Figure 6. Patient and caregiver attitudes and understanding of biomarker testing, sources for biomarker information and suggested improvements



[a]Multiple responses possible

TAKE-HOME MESSAGES

Biomarker testing in NSCLC is becoming commonplace but remains inconsistent across regions and centres. Among patient-respondents, 88% had a tissue or blood sample taken for biomarker testing, with some regional and centre-based variation: 96.0% in North America, 83.8% in Europe and 80.0% in other regions; 89.6% in academic vs 83.7% in non-academic centres. Among those patients (in total, by region or by centre) who provided samples for biomarker analysis, nearly all (97.8%) were tested at diagnosis, compared with 15% at progression and 5.8% at recurrence.

The survey confirmed that biomarker testing results are predominantly used to guide treatment in patients with NSCLC, with 94.4% (group size: n = 196) indicating that treatment was guided by the availability of biomarker testing results.

Despite positive data supporting adoption and use that includes testing at diagnosis and a demonstrated willingness among care providers and patients to utilise biomarker testing to guide treatment, significant challenges persist that limit its real-world clinical impact, including delays in results availability, variability in testing practices, and inconsistent communication.

In particular and considering the important role that NGS can play in biomarker testing in NSCLC, our results show that there is an underutilisation of this technology in clinical practice, and that many people with NSCLC (or their caregivers) remain unaware of the available options for biomarker testing. This underutilisation is most notable in Europe and other survey regions when compared to North America, where NGS use is markedly higher, and in non-academic centres (vs academic centres) across all regions included in the survey.

Several barriers to the use of NGS have been described in literature, and although organisational-level issues (e.g., technological and financial) may play a more predominant role, at an individual level, contributing factors include lack of shareable educational materials, limited understanding, insufficient time to discuss testing and treatment options, or general patient/family resistance to testing.[7,8]

While many respondents reported improved understanding following biomarker testing, substantial gaps in knowledge and satisfaction remain, highlighting shortcomings in how results and their therapeutic implications are conveyed. In addition, persistent gaps in patient and caregiver understanding highlight the need (and perceived need on the part of the patient or caregiver) for faster turnaround times and clearer, patient-centred communication to ensure biomarker testing that meaningfully informs treatment decisions and improves NSCLC care. These findings underscore an urgent need to streamline biomarker testing workflows, improve coordination across multidisciplinary teams, and enhance communication practices.

The survey revealed a substantial improvement in patient and caregiver knowledge levels following biomarker analysis, with significant increases in the proportions of participants categorised as 'very knowledgeable' and 'somewhat knowledgeable'. However, approximately 5.8% of patients and 13.9% of caregivers remained 'not knowledgeable' or 'unaware' of biomarker testing. So, while survey findings reflect encouraging progress, they underscore the ongoing need for enhanced educational initiatives to further support both patients and caregivers in understanding this critical aspect of cancer care.

Overall, there seems to be a need for clear and effective communication. This relies not only on healthcare professionals having the necessary communication and perception skills but, importantly, on their judgment as to when and how to use them.[9] Beyond improving the quality of communication, avoiding misinformation is also critical, as this translates to divergent expectations, intentions, and outcomes between clinicians and the people they treat and those in a caregiving capacity.[10]

Encouragingly, many survey participants interacted with cancer advocacy groups, which play a key role in education and trial engagement.[11,12]

Final word

Biomarker testing is an integral part of a quality NSCLC diagnostic pathway and helps to determine optimal disease management and care that, when supported by adequate education, is highly valued by patients with NSCLC and their caregivers.

Although focused on NSCLC, these insights are likely applicable across other cancer types, suggesting broader opportunities to strengthen the integration of precision oncology into routine clinical practice and ultimately improve patient outcomes.

Abbreviations

EGFR	Epidermal growth factor receptor;
IASLC	International Association for the Study of Lung Cancer;
ILCF	The Israeli Lung Cancer Foundation;
ISLB	International Society of Liquid Biopsy;
LuCE	Lung Cancer Europe;
NGS	Next-generation sequencing;
NSCLC	Non-small cell lung cancer;
NTRK	Neurotrophic tyrosine receptor kinase.

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