Summary Report: Survey Findings from LUNGevity Foundations Annual HOPE Summit, May 2026

Introduction & Methodology

1. Purpose of the Survey

The study objective is to utilize LUNGevity Foundation's annual in-person patient and caregiver summit, HOPE Summit, to learn from the community about pressing issues that people with lung cancer may be experiencing in a rapidly changing diagnostic and treatment landscape.

In 2026, our survey was designed to answer the following research questions.

Topic	Questions
1. Biomarker testing and delays for clinical trials	• What are patients willing to do when a clinical trial requires, a) retesting, or b) re-doing biomarker testing • What amount of time are they hypothetically willing to wait
2. New terms in lung cancer treatment	• What terms are people familiar with • How familiar are they with the terms • Learn how this has shifted since 2024 when we asked some of these terms
3. Artificial intelligence and patient care	• What is people's awareness of AI[1] • How comfortable are people with AI tools in clinical trial informed consent • What are their attitudes toward AI in their cancer care[2]
4. Other (i.e., alternative and complementary) therapies/ care	• Learn what complementary and alternative medicine (e.g., herb, vitamins) people utilize and activities people participate in (e.g., meditation, yoga) to help with their cancer care • Learn if they talk with their health care team beforehand

[1] U.S. PUBLIC ATTITUDES ON ARTIFICIAL INTELLIGENCE https://lsc.wisc.edu/wp-content/uploads/sites/876/2025/04/22-05-04_scimep_AI-topline_socarxiv-submission.pdf (accessed 4/6/2026)

[2] Adapted for cancer from Naik, Sachin, et al. "Patients' Acceptance and Intentions on Using Artificial Intelligence in Dental Diagnosis: Insights from Unified Theory of Acceptance and Use of Technology 2 Model." *International Dental Journal* 75.6 (2025)

2. Context of the HOPE Summit and Survey

The annual HOPE Summit took place in Dallas, Texas on the first weekend of May 2026. There were 160 patients and caregivers in attendance for the weekend summit where education sessions, interactive workshops and community building make up the agenda. Each year, the Patient- Focused Research Center conducts a variety of research projects that are intended to learn about relevant, timely topics to the lung cancer community. The focus groups (described in a separate report) and surveys aim to meet the overarching objective of utilizing LUNGevity Foundation's annual in-person patient and caregiver summit, HOPE Summit, to learn from the community about pressing issues that people with lung cancer may be experiencing in a rapidly changing diagnostic and treatment landscape.

3. Survey Design & Method

At the 2026 HOPE Summit, an anonymous patient and caregiver paper survey was administered. The patient survey included 32 questions and the caregiver survey included 28 questions. All questions from the patient and caregiver survey were the same, except for deviations of wording to reflect the appropriate respondent. For the sections on biomarker testing and clinical trial delays and AI items, caregivers were asked to think through the questions hypothetically from their viewpoint. Caregivers were asked to respond about the person they care for in terms of disease characteristics (e.g., stage), treatments, biomarker testing, and complementary medicine use. One hundred and twenty-eight surveys were turned in, with 88 from patients and 40 from caregivers.

The overall response rate was 80% with 128 participants. Data from the paper surveys were entered online using forms set up in Qualtrics and analyzed using Stata 19.

Key Findings

4. Summary of Survey Results

Demographics

Most participants were aged between 51 and 60 (28%), identified as female (75%), were White (76%) and had achieved a graduate education (35%). Participants were mostly retired (31%) or working full-time (30%), but 12% reported being unable to work. Nearly half of the sample (44%) were residing in suburban areas, with about a quarter in large cities and the other quarter in small town/rural areas (see Table 1).

Table 1. Participant demographic characteristics by patient and caregiver

	Patient (n = 88)	Caregiver (n = 40)	Total (n =128)
Age			
30 or younger	0	5%	2%
31-40	11%	5%	9%
41- 50	19%	22%	20%
51-60	29%	25%	28%
61-70	23%	22%	23%
71-80	15%	15%	15%
Older than 80	2%	5%	3%
Gender			
Female	83%	37%	75%
Male	15%	59%	22%
Other	0	0	0
Prefer not to disclose	0	2%	1%
Missing	2%	2%	2%
Race/ethnicity*			
White/Caucasian	77%	73%	76%
Black/African American	9%	8%	9%
Asian	6%	10%	7%
Hispanic/Latino	1%	5%	2%
Other	1%	3%	2%
Prefer not to disclose/Missing	6%	3%	5%
Education			
Less than HS	0	2%	1%
HS/GED	3%	7%	5%
Some college/tech school	18%	10%	16%
College/tech school graduate	44%	30%	40%
Grad/professional school	30%	48%	35%
Prefer not to disclose	1%	2%	2%
Missing	3%	0	2%
Employment			
Work full time	23%	47%	30%
Work part time	9%	10%	9%
Self-employed	3%	13%	6%
Unemployed	7%	2%	5%
Retired	35%	22%	31%
Student	0	0	0
Unable to work	17%	0	12%
Prefer not to disclose	2%	5%	3%
Missing	3%	0	2%
Geographical region			
Large city	26%	25%	26%
Suburban near a large city	47%	37%	44%

Small city or town	19%	30%	23%
Rural	6%	5%	5%
Missing	2%	2%	2%

* Note: race and ethnicity were select all that apply

Most participants reported their cancer was stage IV (54%) and were taking targeted therapy (56%) either as a monotherapy or in combination with other treatments. To see additional clinical characteristics, see Table in Appendix.

Biomarker Testing Delays for Clinical Trials

We asked participants to report how different situations might influence their decision to join a clinical trial. There were three hypothetical scenarios (tumor biopsy and/or additional biomarker testing might delay starting a new treatment by either 3 or 5 weeks) and three response options for each scenario. In every scenario, larger proportion indicated that a five-week wait would affect their decision.

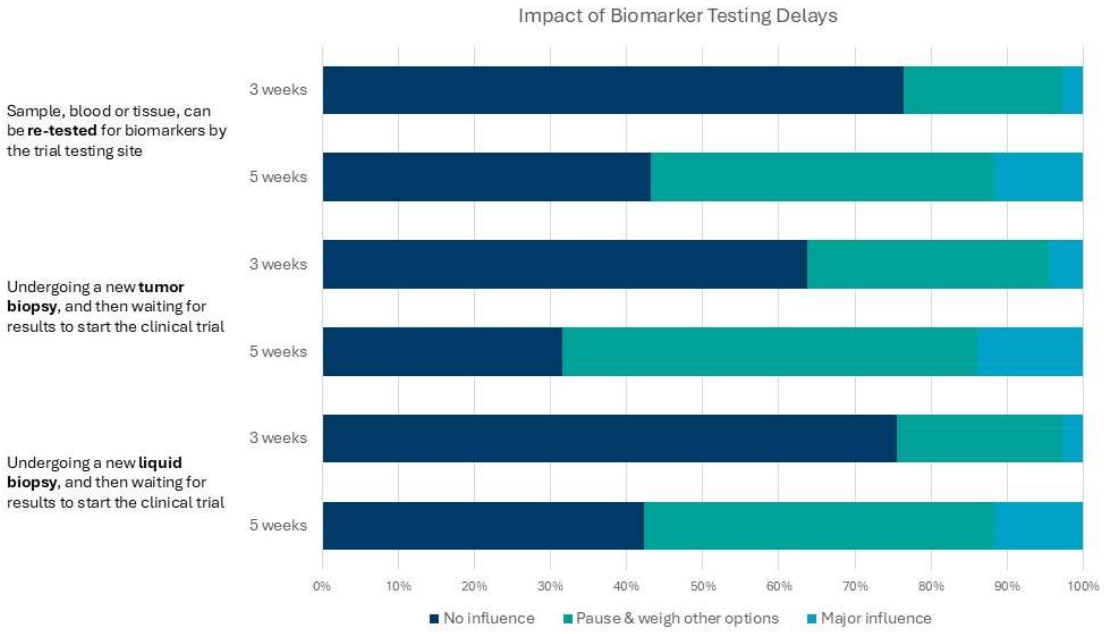

Figure 1. Impact of Biomarker Testing Delays

Participants were presented with the option of sharing their thinking behind their selections via an open text box. Some of the participants who were willing to wait longer focused on their trust in their doctor and desire to find a successful treatment:

- *"I would imagine if put in that position my dr would have a valid reason for me to be in that particular trial and the wait would be necessary"*
- *"I would do almost anything to beat my disease"*

Those who were more concerned about the wait focused on how quickly things can change for patients living with lung cancer:

- *"While EGFR can be considered "slow" to mutate, progressions can occur quickly (2-3 months). Delaying beyond 3 weeks feels risky - it's 100% unsettling to the patient"*

Implications and opportunities:

These are real-world decisions that many individuals living with lung cancer may face when deciding whether to join a clinical trial. Patients seeking enrollment in lung cancer clinical trials are often required to repeat biomarker testing, adding three to five weeks for sample processing and results. In some cases, a new biopsy is also required, increasing patient burden and further delaying trial enrollment. Patients' reported hesitancy toward enrollment in the face of these hurdles demonstrates sample biomarker re-testing (and in some cases a tissue re-biopsy) as a barrier to patient access to clinical trials and novel treatments. LUNGevity is working to advance innovative policy solutions to support more flexible biomarker testing approaches for trial enrollment.

Learning About New Terms in Lung Cancer Treatment

As lung cancer diagnostics, treatments, and supportive care continue to improve and change it is important to check with the community to better understand what terms are generally comprehensible and where there is opportunity to create education materials to support our community. We asked HOPE Summit attendees in 2024 about their familiarity with a series of terms. Over the past two years we see that more attendees were aware of terms like *antibody drug conjugate* and *HER2 gene changes* (both in lung and breast cancer). However, some terms were less familiar to the 2026 HOPE Sumit attendees. For example, *multi-cancer early detection test* and *bispecific antibody*. When participants were asked how they learn best about their disease, the majority (75%) selected "public website", followed by webinars with experts (60%).

Table 2. Proportion of participants reporting familiarity with terms by the 2026 and 2024 HOPE Summit participants

Terms	Any familiarity 2026 (n=128)	Any familiarity 2024 (n =90)
Infusion reaction	59%	56%
mRNA cancer vaccine	57%	Not asked
HER2 gene changes in lung cancer	55%	47%
HER2 gene changes in breast cancer	51%	48%
Accelerated approval	49%	40%
CAR-T therapy	46%	Not asked

Antibody-drug conjugate	43%	28%
Multi-cancer early detection test (MCED)	30%	34%
Radiopharmaceutical therapy	30%	Not asked
Tumor treating fields	28%	Not asked
Off-the-shelf vaccine	27%	21%
Tumor-infiltrating (TIL) therapy	24%	Not asked
Bi-specific T-cell engager (BiTE) therapy	22%	Not asked
Bispecific antibody	19%	23%

Opportunities: These findings highlight an opportunity for LUNGevity to create additional educational materials, webinars, and social media content about these terms, especially since the most familiar term ('infusion reaction') was familiar to just over half (59%) of the HOPE Summit attendees this year. Most participants expressed interest in learning through website-based resources or expert-led webinars. LUNGevity is well positioned to meet this need by developing educational content and leveraging the Gateways platform to disseminate these materials.

Artificial Intelligence & Care

General Perceptions of Artificial Intelligence

Before asking about the use of AI in clinical trials and patient care, we first asked participants how much they felt they knew about AI in general. The majority of participants rated themselves as "somewhat informed" or higher when asked how informed they were on the *Impacts of AI on Society* and *Concrete Uses/Applications of AI*. This generally suggests that this HOPE Summit sample was savvy in terms of AI.

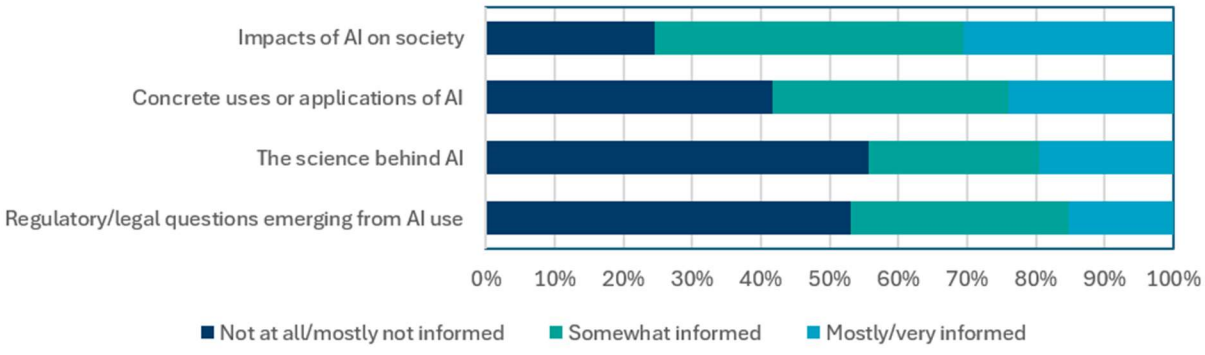

Figure 2: Stacked bar chart describing the proportions of participants reporting how informed they feel on high-level AI concepts

There did not appear to be any large differences across different age groups in the distribution of how informed people felt. Reinforcing that this was a generally well-informed sample (Figure 3).

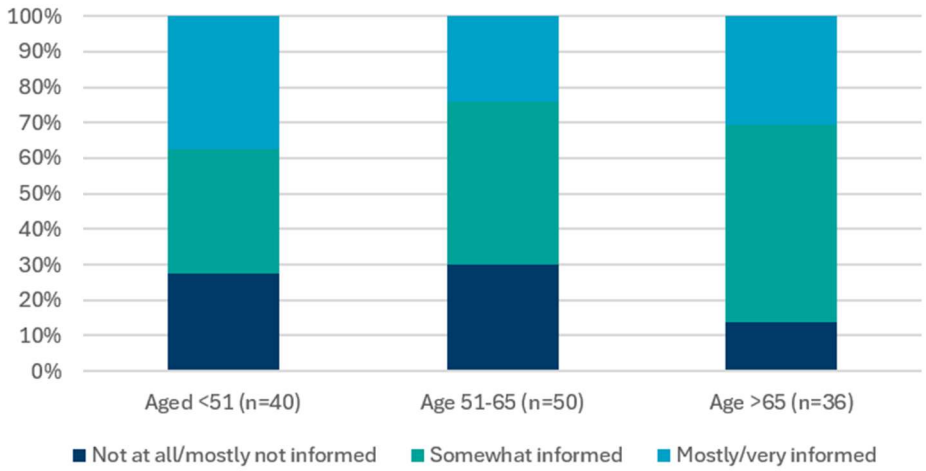

Figure 3: Stacked bar chart describing the proportions of participants by age on how informed they felt regarding the impacts of AI on society

Role of AI in Clinical Trial Informed Consent Process

Participants were asked to imagine a hypothetical scenario where they were considering a clinical trial where an AI tool would:

- Explain medical terms in plain language,
- Summarize risks and procedures,
- Suggest questions to ask your doctor, but not advise on whether to join the trial or not

Participants reported being somewhat comfortable through very comfortable with the AI tool describing the risks, potential benefits, and side effects (<10% reported being not at all comfortable) as well as trial procedures (12% selected “not at all comfortable”). There is less comfort with the tool describing alternative treatment options (20% were not comfortable with this scenario). However, when it came to describing privacy considerations, 40% were not comfortable with the tool describing this information.

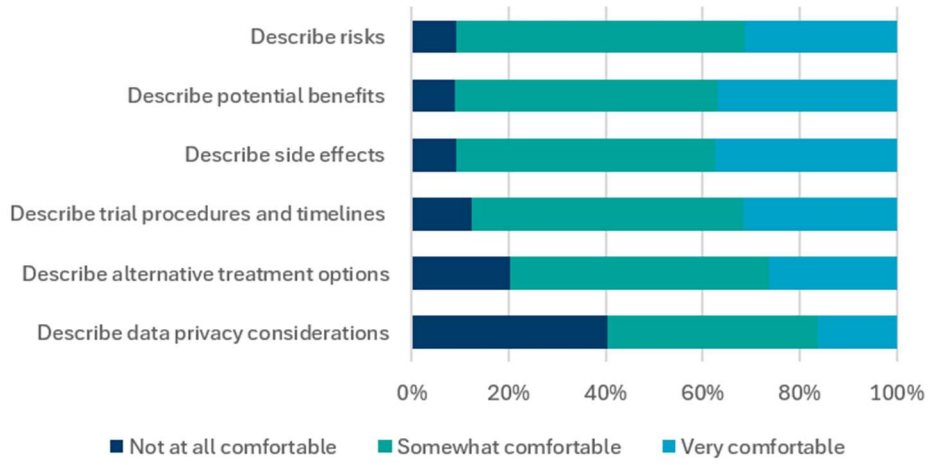

Figure 4: Stacked bar chart describing the proportions of participants with varying comfort using an AI tool as a part of the ICF process

Participants were asked whether they would be disappointed if the AI tool was unable to provide actionable trial recommendations. Responses were mixed, with 48% reporting they would not be disappointed, 38% indicating they were unsure, and 14% saying they would be disappointed. Of those who would be disappointed, they were more likely to report not being comfortable with different components of AI. Regardless, the overwhelming majority (92%) reported wanting input from their clinical team about whether they should participate in the clinical trial.

Opportunities: Overall, AI can help patients understand clinical trials, but important decisions should remain in partnership with healthcare professionals. As a Foundation, we should be promoting "human-in-the-loop" models where AI can be used to provide information while clinicians answer questions and provide recommendations. There appears to be a particular priority around privacy, and it could be useful for LUNGevity to have educational materials or a webinar around privacy and AI both for clinical trials as well as medical data.

Artificial Intelligence in Clinical Care

To assess perceptions of AI in clinical care, we adapted the Unified Theory of Acceptance and Use of Technology 2[3] survey to relate to cancer care. Patients completed this survey in terms of their care, whereas caregivers were asked to complete the survey hypothetically. For simplicity, we just report on the patient (n=88) sample.

Over 40% of patients agreed that AI would improve the accuracy of their treatment and help their oncologist to make better decisions, indicating broad support of AI. However, patients were split on whether using AI as a part of their healthcare was “exciting” for them (disagree = 34%, neutral = 27%, agree = 39%).

We wanted to understand whether people with different levels of knowledge about AI viewed its use in cancer care differently. To do this, we compared how often participants who considered themselves very informed, moderately informed, or not informed agreed with nine statements about AI and their care. Most notably, people who reported being very informed on AI issues were considerably more likely to agree that AI will help their oncologist make better decisions and that they are comfortable using AI during their appointments. The differences were smaller when asked about whether there is a general belief among patients that AI can improve diagnosis, whether they prefer a clinic that uses AI over a clinic that does not and whether their clinic has the resources to implement AI effectively. This in part tells us that being informed about AI does not necessarily mean

[3] Naik, Sachin, et al. "Patients’ Acceptance and Intentions on Using Artificial Intelligence in Dental Diagnosis: Insights from Unified Theory of Acceptance and Use of Technology 2 Model." *International Dental Journal* 75.6 (2025)

support for AI in care and that there are other factors impacting participants' support of AI as a part of their care or not.

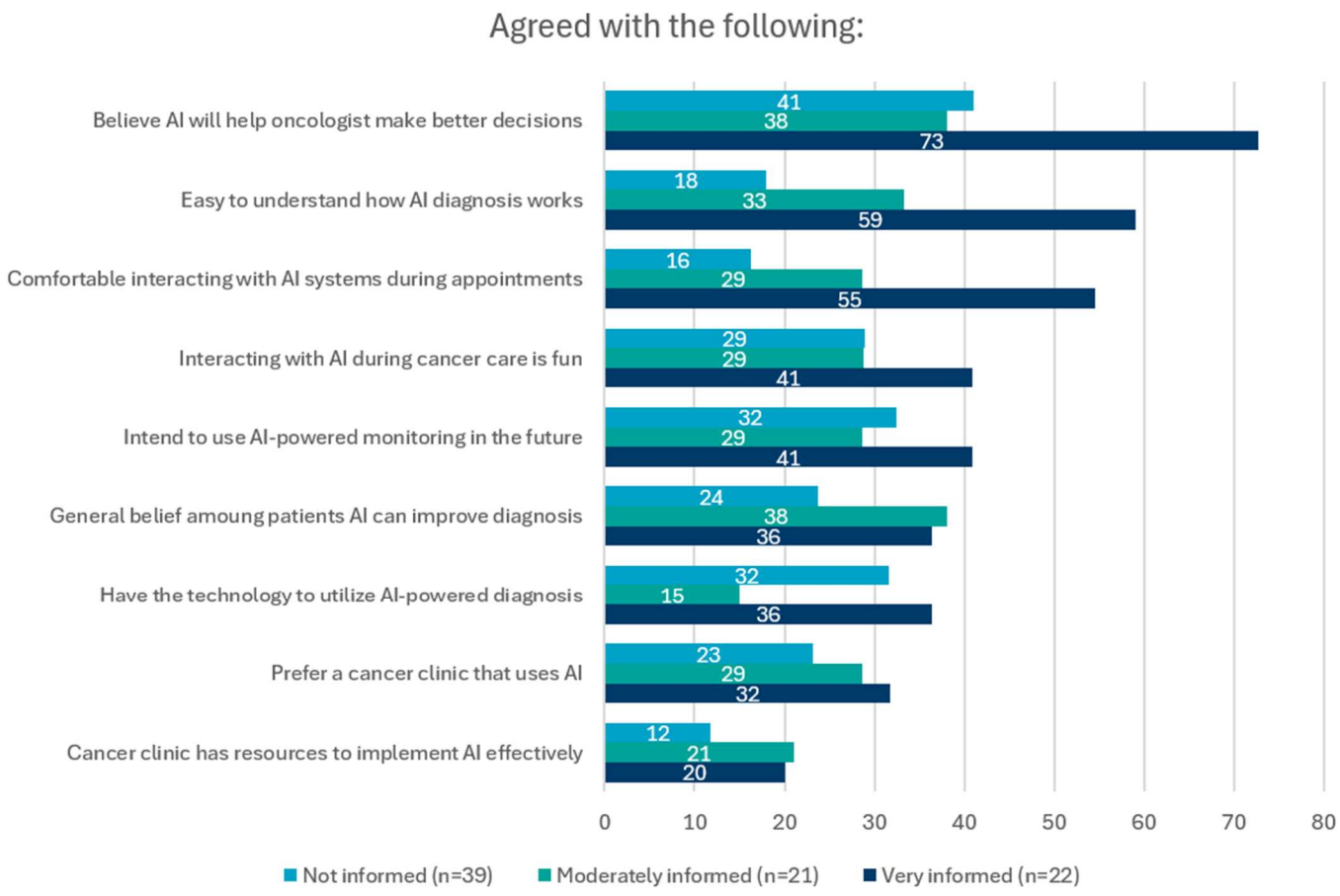

Figure 5. Proportion of participants who agree with statements on AI in their cancer care by how informed they reported being on issues surrounding AI

Opportunities: Patients who feel that they understand AI and are informed on AI issues are more likely to feel comfortable with the use of AI their care. LUNGevity could create a series of educational materials on uses of AI in lung cancer care. As there were participants who emphatically reported:

> *"I do not want to rely on AI. I want a doctor that's educated and experienced and not just googling!"*

We can also advocate for healthcare systems to disclose when AI tools are being used in care. These findings are also indicative of a general sentiment that AI should strengthen the relationship between patient and oncologist and not replace it. As one patient shared:

> *"Everyone and everything to better my outcomes to live a quality life. [pie chart with thirds: clinical team - AI - me]"*

Overall, it appears that patients were open to AI in cancer care, but acceptance depends on education, transparency, trust, and meaningful patient involvement.

Complementary and Alternative Medicines and Supportive Care

A list of complementary supportive care options were presented and participants asked if they had used each of the options in the past 12 months and whether they spoke with their healthcare team before using it. All 16 of the options presented in the survey were used in the past 12 months by some participants. Supplements, including herbs, vitamins, and homeopathic remedies, were commonly used by participants. Vitamins were the most commonly reported supplement, with around half of participants reporting some supplement use. However, 61% of those taking vitamins had not checked in with their health care team before using them. Other complementary therapies including meditation, yoga, and massage, were also widely used, and many participants had not discussed these practices with their healthcare providers. While activities such as meditation are generally less likely to have direct clinical consequences, some orally consumed supplements can interact significantly with cancer treatments. For example, St John's Wort is known to affect the effectiveness of certain medications. Similarly, complementary therapies such as massage may not be risk-free and are ideally provided by practitioners experienced in working with people living with cancer.

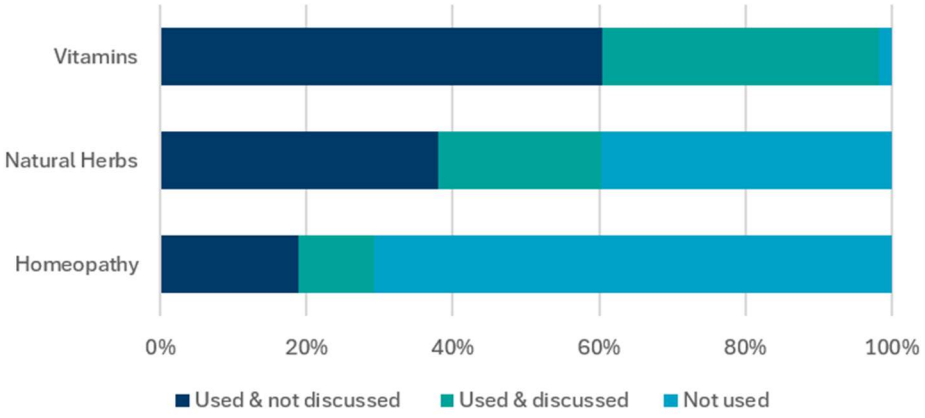

Figure 6: Stacked bar chart for patient participants who reported using at least 1 type of supplement and whether they discussed using the supplement with their healthcare team

We also asked people to report if they chose not to disclose to their healthcare team something they had ingested: 11% of patient participants reported yes to this question. This raises concerns, as there is a growing online trend to use parasitic treatments (ivermectin and fenbendazole) as a part of cancer care. There is no in-human evidence that these are effective in treating cancer.

Opportunity: This finding highlights a potential gap in trust and communication that may place patients at risk, particularly as misinformation about cancer treatments circulates

widely online. Creating trusted, judgment-free spaces for patients and caregivers to ask questions may help reduce the likelihood of undisclosed supplement or medication use. While we did not specifically ask about parasite treatments, there is room for LUNGevity to host a potentially anonymous *Ask Me Anything* style webinar to dispel myths about different types of supplements and over-the-counter medications, and to discuss why speaking with your healthcare team is critical.

Conclusion

All findings here are likely an underrepresentation of the problems the greater lung cancer community experiences. Yet, these data provide an important window into how those who attend our HOPE Summit are experiencing and navigating their lung cancer diagnosis.

Thank You and Acknowledgements

We appreciate the patient and caregiver HOPE Summit attendees' willingness to complete our survey.

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Appendix

Table 1 Appendix: Participant clinical characteristics by patient and caregiver

	Patient (n =88)	Caregiver (n =40)	All participants (n =128)
Year Diagnosed			
Median (Min – Max)	2022 (2003-2025)	2023 (2008-2025)	2023 (2003-2025)
Missing	4	0	4
Histology			
Adenocarcinoma	75%	70%	73%
Small cell lung cancer	10%	15%	12%
Squamous cell	2%	0	2%
Unspecified	1%	2%	2%
Mixed histology	3%	5%	4%
Other	2%	8%	4%
Missing	3%	0	2%
Stage			
Stage I/II	7%	10%	8%
Stage III	4%	0	3%
Stage IV	57%	47%	54%
LS-SCLC	2%	5%	3%
ES-SCLC	4%	7%	5%
NED			
Initially Stages I-III	44%	33%	41%
Initially Stage IV	44%	56%	48%
Initially SCLC	11%	11%	11%
Do not know	1%	2%	2%
Missing	1%	0	1%
Initial biomarker testing at diagnosis			
Yes, and has a biomarker	75%	67%	73%
Yes, and doesn't know	0	0	0
Yes, and does not have a biomarker	5%	8%	5%
No, not tested	15%	22%	17%
Do not know	4%	3%	4%
Missing	1%	0	1%
Biomarkers reported	**Patient (n =66)**	**Caregiver (n =27)**	**All (n =93)**
EGFR	38%	59%	44%
ALK	20%	15%	18%
KRAS	3%	4%	3%
PD-L1	6%	0	4%
HER2	12%	7%	11%
RET	8%	4%	6%
More than 1 biomarker	12%	11%	12%
Missing	2%	0	1%

Treatment status	Patient (n = 88)	Caregiver (n =40)	Total (n =128)
Diagnosed, not begun treatment	1%	0	1%
Currently in treatment	56%	45%	52%
Completed treatment	9%	2%	7%
Cont. treatment & NED	17%	25%	20%
Completed treatment & NED	8%	17%	11%
Recurrence with additional treatment	5%	5%	5%
Other	5%	3%	4%
Missing	1%	0	1%
Current treatments			
No treatment	24%	20%	23%
Targeted therapy only	40%	25%	35%
Chemotherapy only	2%	0	2%
Monotherapy IO	6%	10%	7%
ADC	2%	0	2%
Chemotherapy + IO	0	0	0
Chemotherapy + TT	5%	7%	5%
TT + radiation	1%	3%	2%
Clinical trial	8%	7%	8%
Other	10%	22%	13%
Missing	1%	5%	4%
Insurance			
Employer paid insurance	36%	42%	38%
Private marketplace	9%	10%	9%
Medicare	31%	22%	28%
Traditional Medicare (Parts A/B)	47%	62%	51%
Traditional Medicare plus Medigap	29%	38%	31%
Medication Therapy Management program/Drug coverage (Part D)	24%	23%	23%
Medicare Advantage	29%	8%	23%
Do not know	0	8%	<1%
Medicaid	1%	5%	2%
Medicare + Private	8%	10%	9%
Medicare + Medicaid	2%	0	2%
Tricare/champs/VA	2%	2%	2%
Other	7%	0	5%
Do not know	0	5%	2%
Missing	3%	2%	3%

ES-SCLC, Extensive stage, small cell lung cancer; NED, No evidence of disease; IO, Immunotherapy; TT, Targeted therapy; VA, Veteran's Affairs

*No respondents marked BRAF, CDK4/6, MEK1, MET, NRG1, PIK3CA,, RIT1, those with two or more had at least either EGFR or PD-L1 as part of the combination

About this survey: Survey questions came from a variety of sources. For example, the demographic and clinical characteristics are the same questions we have used across the years in the survey. The questions about awareness of AI came from the University of Wisconsin- Madison report on U.S. Public Attitudes on Artificial Intelligence[4]. The questions about attitudes toward AI were adapted from dental care to cancer care for this survey[5]. All other questions were created specifically for this survey by LUNGevity.

[4] U.S. PUBLIC ATTITUDES ON ARTIFICIAL INTELLIGENCE https://lsc.wisc.edu/wp-content/uploads/sites/876/2025/04/22-05-04_scimep_AI-topline_socarxiv-submission.pdf (accessed 4/6/2026). Accessed June, 8th, 2026

[5] Adapted for cancer from Naik, Sachin, et al. "Patients' Acceptance and Intentions on Using Artificial Intelligence in Dental Diagnosis: Insights from Unified Theory of Acceptance and Use of Technology 2 Model." *International Dental Journal* 75.6 (2025)