



Molecular Testing in Lung Cancer: Patient and Caregiver Experiences

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LUNG CANCER ALLIANCE

INTRODUCTION

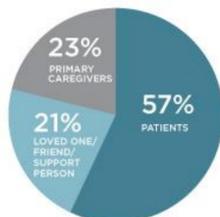
Increasingly over the past decade, new targeted therapeutics and immunotherapies with associated companion diagnostics have been approved for the treatment of lung cancer. Lung cancer is often associated with elderly and lower socio-economic populations that may not have a high level of health literacy. With the advent of new therapies, molecular testing/biomarker testing has become an increasingly critical part of lung cancer treatment planning. As part of a needs assessment of the lung cancer community, we examined whether appropriate testing was taking place in the community.

METHODS

A “Lung Cancer Community Needs Assessment” anonymous online survey was developed by Lung Cancer Alliance (LCA) and was open to both patients and caregivers from 11/9/2015 to 2/8/2016. The survey was promoted primarily electronically through social media (Twitter and Facebook) and electronic newsletters. The survey URL was also posted twice to the Inspire patient community, once by American Lung Association and once by a caregiver. In addition, 15 long-term survivors known to be without internet access were called by a LCA staff member and 10 of them completed the survey by phone.

RESPONSE RATE

There were **820** total survey responses.



DEMOGRAPHICS

The following demographic data reflects the 471 survey respondents who identified as patients. Demographic questions were optional and the number of respondents is indicated.

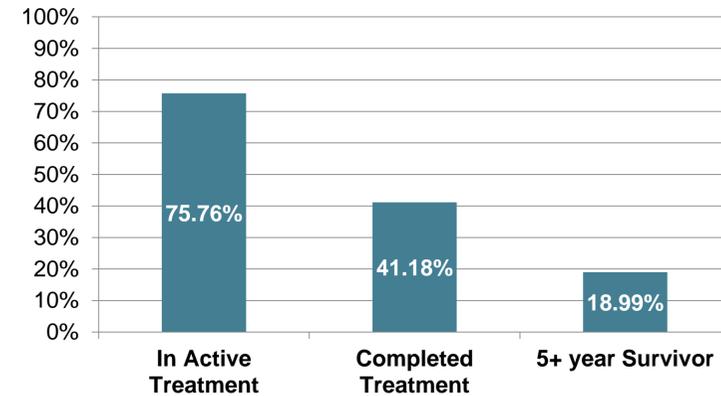
Sex	(n=407)	
Male	68	16.7%
Female	339	83.3%
Race	(n=365)	
White	342	93.7%
Black/African American	7	1.9%
American Indian/Alaskan Native	2	0.5%
Japanese	1	0.3%
Chinese	8	2.2%
Other Asian	2	0.5%
Other	3	0.8%
Ethnicity	(n=302)	
Hispanic/Latino	6	2.0%
Not Hispanic or Latino	296	98.0%
Residential Setting	(n=411)	
Rural	96	23.36%
Suburban	235	57.18%
Urban	80	19.46%
Household Income	(n=363)	
Less than \$20,000	27	7.4%
\$20,000 - \$39,999	41	11.3%
\$40,000 - \$59,999	74	20.4%
\$60,000 - \$79,999	53	14.6%
\$80,000 - \$99,999	50	13.8%
\$100,000 and over	118	32.5%

357 patients (87%) reported having Non-Small Cell Lung Cancer (NSCLC). Of those cancers, patients reported the following characteristics at diagnosis:

Subtype of NSCLC	(n=356)		Stage of NSCLC	(n=356)	
Adenocarcinoma	283	79.5%	Stage I	78	21.9%
Squamous	39	11.0%	Stage II	43	12.1%
Large Cell	1	0.3%	Stage III	82	23.0%
I Don't Know	33	9.3%	Stage IV	147	41.3%
			I Don't Know	6	1.7%

RESULTS

Patients with lung cancer report increased molecular testing for treatment planning over time

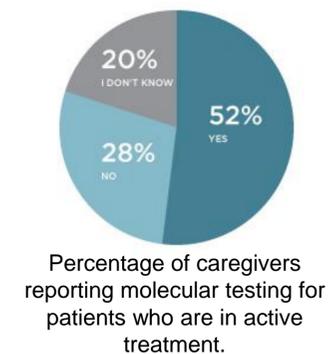


Patient survey respondents were asked, “Did you have molecular testing/biomarker testing to help determine your treatment plan? (Examples include tests for EGFR or ALK mutations/changes or having your tumor tested for changes in a large number of genes).” Percentage of patients answering “Yes” is shown, stratified by current stage of treatment/survivorship.

One out of six patients do not know if they have received molecular testing

	Active Treatment	Completed Treatment	5+ year Survivors	
Yes	150	42	15	
No	24	38	49	
I Don't Know	24	22	15	16% Don't Know
Total	198	102	79	

Caregivers also report increased testing rates, but with less certainty



Caregivers reported a 52% (98/188) testing rate for patients in active treatment vs 31% (4/13) for 5+ year survivors. However, caregivers were less likely to know with 22% across all categories answering, “I Don't Know.”

Some patients who did not have molecular testing still report receiving EGFR targeted therapies

Patients with Stage III/IV NSCLC in active treatment who did not have molecular testing (n=12) reported having taken or currently taking EGFR inhibitors erlotinib (n=4) and afatinib (n=1). Caregivers for this demographic (n=25) also reported use of erlotinib (n=4) and gefitinib (n=1).

CONCLUSIONS

- The rate of molecular testing to determine treatment options for patients with lung cancer has increased dramatically over the past 5 years
- There is still a large educational gap with many patients and caregivers not knowing if testing took place
- The data suggest that some patients are not being treated according to clinical guidelines

FUTURE DIRECTIONS

- This survey is biased by its electronic method of delivery and the dominant demographic of white women. More research needs to be done in other demographics where we hypothesize that the educational gap will be more prominent.
- All stakeholders – including healthcare providers, patient groups and industry – must work to educate patients with lung cancer and their loved ones on the importance of molecular testing for making informed treatment decisions.

ACKNOWLEDGMENTS

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