

**LUNGeVity Barriers to Clinical Trial Participation**  
*as perceived by Lung cancer patients and*  
*caregivers*

### **Summary and Next Steps - Clinical Trial Survey with patients and caregivers**

In summer of 2017, LUNGEvity Foundation surveyed lung cancer patients and their caregivers about participation in clinical trials. A total of 170 patients and 48 caregivers participated in the survey.

Major differences were not seen between the responses of patients and caregivers, but of note is that patients most often would like to receive information on clinical trials from patient advocacy groups, while caregivers most often would like to receive information from the patient's doctor. That only 15% of caregivers reported that they have no decision-making role about the patient's participation in clinical trials indicates how important educating caregivers as well as patients is.

#### **Education gaps:**

Education on clinical trials that cater to both patients **and** caregivers, and discuss resources that are commonly available for participation in clinical trials

## **Patient Survey (Observations and Tabulated Data)**

## Observations from 2017 Clinical Trial Patient Survey

N = 170

### Snapshot of the patient respondents

One hundred seventy patients responded to the survey. The sample size was high enough that the responses fairly represent *this* group, which may not represent all lung cancer patients. This group differs from the general US population in that it:

- is more highly educated than the general US population: about 75% of completion of college and/or graduate school vs. 32%
- has a higher income than the general US population: 49% reported household income of more than \$75,000 vs. 28%

It is reasonable to assume that this group, by their higher socioeconomic level and by their attendance at a LUNGEvity HOPE Summit or their willingness to take an online survey, is a relatively more engaged and informed group than other lung cancer patients. Their reported level of openness to clinical trial participation probably represents the highest level that would be observed among all lung cancer patients.

More of the patients have a diagnosis of NSCLC than in the general lung cancer population (95% vs. 85%), and 79% have stage IV/advanced-stage/metastatic lung cancer.

Eighty-two percent of the survivors reported having their tumors tested for biomarkers. This rate is considerably higher than in the general lung cancer population where testing rates of 65%-70% are reported. Ninety-two percent of those patients who have already participated in a clinical trial reported having had their tumors tested for biomarkers, not surprising since biomarker testing is often a requirement for participation, but the percentage among those who have not participated in a clinical trial is still high: 77%.

Among those who had their tumors profiled, more by far have been tested for EGFR and ALK than any other biomarker; these are the biomarkers for which there are the most FDA-approved treatments. However, about one-third were tested for KRAS and ROS, and testing for other biomarkers, including PD-L1, also occurred, although at lower levels.

Eighty percent of patients who have had biomarker testing reported that the testing was performed before any treatment started. About one-fourth of these patients reported their tumor was profiled at the time of recurrence after first- and second-line therapy.

Among the different treatment approaches, chemotherapy (64%) and targeted therapy (57%) are the most common ones received by patients. Fifty-four percent of the patients have received targeted therapy. Seventy-four percent of the patients have received more than one type of treatment.

### **Desired sources of information about clinical trials**

Patients would like to receive information about clinical trials from multiple sources, but the source preferred by more than any other was patient advocacy groups: 84% selected this source. Online through websites such as [clinicaltrials.gov](http://clinicaltrials.gov) was selected by 65%. More than half (56%) would like to receive information from their doctor. The source patients were least likely to select was companies developing new drugs, but, even so, 38% would like information from them.

## **Clinical trial past and future participation rates**

Twenty-seven percent of patients have previously participated in a clinical trial. The reported participation rate is higher than the rates reported (3%-5%) in the overall cancer survivor community, reinforcing that the patients represent a more engaged population.

Seventy-nine percent of patients reported that they would consider participating in a future clinical trial. Almost all of the other patients reported that they were unsure rather than reporting a definite “no” to consideration. Again, this percentage is probably the maximum response possible among the entire lung cancer patient community.

## **Reasons for clinical trial participation**

Among the 92 patients who provided their own reasons why they would consider participating in a future clinical trial, there are two categories of response: access to treatment options/increase in life expectancy and altruism/advancement of science. Access to treatment options/increase in life expectancy reasons were named more often (samples of responses are included):

### *Access to treatment options/increase in life expectancy (72%)*

Because I'm running out of options.

I'll try anything that keeps me alive!

I'll do almost anything to survive longer for my children.

My cancer is aggressive and nothing I have tried worked for longer than 8 months. I am interested in exploring all options.

A chance for shrinking tumors.

I'm basically out of options. I figure what have I got to lose.

If it comes to survival I will do anything.

Because I want to live as long as I can.

### *Altruism/advancement of science (38%)*

I like being able to help

It may help others.

I also like to feel that I am helping research.

Would like to be a part of finding new treatments.

If no help to me, maybe someone else in the future.

To increase needed research of lung cancer.

I'm alive because someone else did. Paying it forward would honor them.

I would try a drug to further research for others.

Among the 25 patients who provided their own reasons why they are not sure whether they would consider participating in a future clinical trial, the barriers to participation are varied. The largest group, 28% of patients, is not sure because they currently are cancer-free.

### *Currently cancer-free/no evidence of disease (28%)*

If my cancer is in remission, no need.

Cancer free 4 years.

At this time I'm NED.

At this point I am cancer free - 11 years.

*It would depend (20%)*

I would have to weigh risks/benefits.

It would depend on the current state of my health and life style and what was the reason for the trial.

I would have to have a lot of information and discussion about it.

Depends where I am at in treatment response.

*Distance (16%)*

Distance to travel.

I live too far away from the hospital for it to be sustainable.

I'm 77, live a distance from major cancer center.

Distance from home.

If I were a candidate--although NOT at this time.

*Fear (16%)*

The thought of a "trial" treatment scares me, because what if it doesn't work and the cancer spreads? The Unknown.

I am not sure I want to take a chance on a medication that may not work.

Fear of the unknown. My therapy is going well now and I will not want to make changes.

*Miscellaneous (24%)*

I would take doctors recommendation into consideration.

I don't want that much attention and intervention.

Pre-existing NOHCM, diastolic heart failure.

Too many required CT/MRI and blood work. Visits are too often. Do not have time to LIVE my life.

In addition to offering their own reasons for their participation or not in a clinical trial, patients were provided a list of 13 factors that could help them decide whether to participate in a clinical trial. The factors that more caregivers are likely to assign a higher importance score relate to how the clinical trial might affect them:

- Potential side effects
- Whether will know in advance which treatment group will be in
- Scientific rationale for the clinical trial
- If all participants receive the new treatment

Patients were least likely to assign a higher score to logistical factors:

- Number of visits to the study center
- Type and frequency of monitoring tests
- Length of time spent on each visit to study center

Educational materials about a clinical trial need to include both types of information.

**Type of support likely to be needed in order to participate in a clinical trial**

Patients were presented with a list of types of support and assessed each for the likelihood of it being needed in order to participate in a clinical trial in which the patient would visit the study center regularly. At the very top of their list are financial reimbursement for airfare and for hotel accommodations even though, as mentioned earlier, these patients are relatively well-off. Other types of reimbursement are less important to

them. At a middle level of importance are nurse visits to the patient's house or driving to a nearby clinic for blood draws and other tests instead of traveling to the study center.

### **Distance willing to travel to participate in a clinical trial**

There is no trend in the distance that patients would be willing to travel every month to participate in a clinical trial, but more patients (26%) reported that they'd be willing to travel 25-100 miles than any other distance either shorter or farther. Twenty-six percent did not select a mileage range at all but said that how far they would travel would depend.

Among the 43 patients who specified a factor on which the distance they would be willing to travel would depend, cost and availability of financial assistance is the factor most often (47%) named. Next more important (23%) is the potential effectiveness of the treatment. (Samples of responses are included.)

#### ***Cost and availability of financial assistance (47%)***

Go 101-200 miles at my expense, further travels would need reimbursement.

If flights were paid for, I'd participate anywhere.

If expenses were covered, I would travel anywhere.

Depends on flight/hotel cost and how long I'd be away from my family.

If distant, I would need financial assistance for travel.

#### ***Potential effectiveness of the treatment (23%)***

If it would save my life, I would find a way!

Would depend on how promising trial seems.

On the trial drug involved and potential outcome of drug.

Depends on whether the drug is a potential life saver.

#### ***If clinical trial offers only/best treatment option (9%)***

How necessary the treatment is.

I would go anywhere if it is my only choice.

If it were my only option, I would travel as far as needed. Otherwise, would prefer options where I could stay w/in Chicago area.

If this was my only hope, I would consider any distance.

#### ***Patient's health (9%)***

How I am feeling.

On how I am feeling.

On progression of my disease and my health.

On my health.

#### ***Miscellaneous (21%)***

Time for travel and time away from home.

How much I want treatment.

If I have family or caregiver support who can travel with me if needed.

How often I would have to go.

**Tabulations from Clinical Trial Patient Survey**

In summer of 2017, LUNGEvity Foundation surveyed lung cancer patients about participation in clinical trials. A total of 170 patients (125 in-person respondents at the National HOPE Summit and 45 online respondents) responded to the survey.

Response percentages are based on the number of patients who answered each question.

**1. What type of lung cancer do you have? (Select one.)**

Non-small cell lung cancer (NSCLC): Adenocarcinoma	84%
Non-small cell lung cancer (NSCLC): Type unspecified	6
Non-small cell lung cancer (NSCLC): Squamous cell lung	5
Carcinoid or neuroendocrine tumor	2
Other (please specify)	2
Non-small cell lung cancer (NSCLC): Large cell lung cancer	1
Small cell lung cancer (SCLC)	1
Not sure	0
	<b>N=170</b>

**2. Which stage best describes the stage of your disease? (Select one.)**

Stage IV/Advanced-stage NSCLC	67%
Stage I NSCLC	10
Metastatic NSCLC	9
Stage III NSCLC	7
Stage II NSCLC	4
Other (please specify)	2
Limited Stage SCLC	1
Extensive Stage SCLC	1
Not sure	1
	<b>N=169</b>

**3. Was your tumor tested for biomarkers? In biomarker testing (also known as molecular or tumor testing), the doctor removes a small piece of cancer tissue through a biopsy and sends it to a pathology laboratory for testing. Presence or absence of specific biomarkers may help guide treatment decisions, such as use of targeted therapy or immunotherapy. (Select one.)**

Yes	82%
No	11
Not sure	7
	<b>N=168</b>

**4. For what biomarkers was your tumor tested? Select all that apply. Please skip if you have responded NO to question 3.**

EGFR	66%
ALK	50
KRAS	33
ROS	30
Other (please specify)	19
PD-L1	18
MET	14
RET	14
BRAF	13
Not sure	13
HER2	11
NTRK	10
	<b>N = 142</b>

**5. When was testing performed? Select all that apply. Please skip if you have responded NO to question 3.**

Before first-line treatment began	80%
After initial treatment was started, because the cancer came back	19
After second treatment was started, because the cancer came back	5
Not sure	3
Other (please specify)	11
	<b>N = 141</b>

**Other responses to this question are:**

- Partial done at start and full done on initial biopsy samples month later
- After surgery of third cancer
- But didn't get results until treatment started
- Another round during lung biopsies, then pericardial effusion fluid
- Sometime in first 3 months
- At surgery
- At time of diagnosis but RET was discovered when tumor was retested in 2011
- 3 years post treatment upon my request
- Long into treatments – blood biopsy
- But not shared with pt/only discovered that testing was performed and came back EGFR+ at 2nd opinion Dr. visit

**6. What treatments have you ever received (either currently or in the past) for lung cancer? (Select all that apply.)**

Chemotherapy	64%
Targeted drug therapy (drug that attacks a specific mutation, e.g., Tarceva)	57
Radiation therapy	54
Surgery	38
Palliative care (treatment of symptoms of lung cancer or side effects of treatment)	18
Immunotherapy (drug that helps the body recognize and fight the lung cancer, e.g., Opdivo)	17
Angiogenesis inhibitor (drug that stops the growth of new blood vessels that feed the tumor, e.g., Avastin)	8
Other (please specify)	5
Not sure	0.6
	<b>N = 168</b>

**7. Have you ever participated in a clinical trial of a new drug for your type of lung cancer? (Select one.)**

Yes	27%
No	73
Not sure	0
	<b>N = 168</b>

**8. Would you consider participating in a future clinical trial of new drug for your type of lung cancer? (Select one.)**

Yes	79%
No	2
Not sure	19
	<b>N = 168</b>

**9. Please explain the reason for your answer in question 8 (Why/Why Not?).**

**Among the 119 who provided a reason for their answer, reasons included:**

**Among those who said YES (N=87)**

*Access to treatment options/increase in life expectancy (72%)*

Four episodes I would try almost anything.

Because I'm running out of options.

I'll try anything that keeps me alive!

Some day it may be my only option - that or give up!!

If I was out of FDA approved options.

I'll do almost anything to survive longer for my children.

The only way to fight this.

If I had no other options.

My cancer is aggressive and nothing I have tried worked for longer than 8 months. I am interested in exploring all options.

I am willing to try anything that could help either reduce my tumors or keep them stable.

In some circumstances, benefits outweigh the risks.

Because it might be my last option or my best option.

If it became my last viable option. If no other treatment was effective. Or if my doctor felt it was a better option than others.

Because I might not have a better option.

A chance for shrinking tumors.

I'm basically out of options. I figure what have I got to lose.

Because I am in second line treatment and not sure what next.

Clinical trials will be the difference between life and death for me, as I am ALK positive.

It if would improve my condition.

If it was my only option, obviously, since it's still experimental.

If it comes to survival I will do anything.

Because I want to live as long as I can.

Anything to extend life expectancy.

To live longer.

Live longer.

To extend my life expectancy.

If there is a drug that might help, I will try it.

If no other choice why not.

Better chance and less invasive.

Always looking for more hope and options!

I want more options, especially since my tumor was not bio marked in 2010.

If it seemed reasonable I would do it.

Because some of the new ones are the best!

Clinical trials are our hope for newer treatments.

To get an innovative treatment.

Because some drugs may work better than some drugs that didn't.

I know that there are no good current therapies for KRAS.

I am stage IV advanced. I do not have a lot of traditional treatment options left any longer.

More options are being made available.

It's the newest advancement + there are no other approved drugs for me.

Sales pitch "Clinical trials deliver tomorrow's medicine to patients today." It saved my life.

It gives me access to new life saving therapies and diagnostics. It is hope.

To have access to treatment combinations (I am on my 8th line/combo). I want to continue living with a good quality of life.

My situation warrants an aggressive approach.

Monitored more often, closer, add one more treatment to my line of FDA-approved drugs/treatment.

When the trial offers benefits that I think are important to my life goals.

Best option for benefit to me.

Clinical trials expand tx choice.

If previous treatments had stopped working and I needed new options I would certainly try a clinical trial.

Because I would something available if this treatment fails.

If I have a recurrence I will definitely participate in a trial.

If cancer returns.

Only if current treatment is no longer working.

Right now, I am NED but if I have a recurrence, I would consider it for RET.

At points of progression? Most definitely.  
If what I am being treated with stops working  
I expect to participate in a clinical trial again due to cMET.  
Clinical trial extended my life and provides access to treatments I would not otherwise be able to have.  
Could help me.  
I would try a drug if I felt I might have a longer life.  
To gain potential benefit.  
To help find a cure for me.  
I'm all for doing it for my own benefit.  
The possibility of new success for me.  
I'm open to trying anything that my oncologist thinks would be best for me.

*Altruism and Advancement of Lung Cancer Research (38%)*

I like being able to help  
It may help others.  
I also like to feel that I am helping research.  
Would like to be a part of finding new treatments.  
We need to participate to further research and treatment.  
Could help others.  
Because research of new drugs to help fight lung cancer is so important.  
For research purposes.  
I'm glad to help with research and appreciate the life-saving treatment I've received in clinical trials.  
If no help to me, maybe someone else in the future.  
To increase needed research of lung cancer.  
I'm alive because someone else did. Paying it forward would honor them.  
To help future lung cancer.  
I would try a drug to further research for others.  
I have seen how much it helps for the future.  
The trials are the only path to progress.  
Help find new treatment options.  
I want research. The more we learn the more likely we are to beat this.  
To help further research knowledge.  
Hope.  
Hope.  
More help for lung cancer.  
Because this is the only way to find out if drugs not approved by the FDA can be effective and then approved.  
To help find a cure for others.  
For the benefit of so many others going forward.  
Potentially helping lung cancer community, assisting research for lung cancer.  
The possibility of new success for others.  
Hope!  
Because it helps all survivors! We can't get new treatments if we don't try!  
Help further research!  
I feel research is important.  
I'd also like to help advance research for others.  
It allows me to give back.  
I want to help advance cancer research for future treatments.  
To help out development of LC treatments.

**Among those who answered NOT SURE (N=25)**

*Currently cancer-free/No Evidence of Disease (28%)*

If my cancer is in remission, no need.

Cancer free 4 years.

At this time I'm NED .

At this point I am cancer free - 11 years.

I probably would if my meds stopped working.

LC not active at this time.

Not a candidate at this time.

*It would depend (20%)*

I would have to weight risks/benefits.

It would depend on the current state of my health and life style and what was the reason for the trial.

I would have to have a lot of information and discussion about it.

Depends where I am at in treatment response.

Depends on cost, travel, and how I am at time.

*Distance (16%)*

Distance to travel.

I live too far away from the hospital for it to be sustainable.

I'm 77, live a distance from major cancer center.

Distance from home.

If I were a candidate--although NOT at this time.

*Fear (16%)*

The thought of a "trial" treatment scares me, because what if it doesn't work and the cancer spreads? The Unknown.

I am not sure I want to take a chance on a medication that may not work.

Fear of the unknown. My therapy is going well now and I will not want to make changes.

*Miscellaneous (24%)*

I would take doctors recommendation into consideration.

I don't want that much attention and intervention.

Pre-existing NOHCM, diastolic heart failure.

If it applied.

Too many required CT/MRI and blood wok. Visits are too often. Do not have time to LIVE my life.

Previous trial drug allowed mets to the brain--too many for cyber knife radiation.

**Among those who answered NO (N=2)**

I am NED.

Worried it will hurt other organs.

**10. How would you like to receive information about clinical trials? (Select all that apply.)**

From patient advocacy groups (e.g. LUNGevity)	84%
Online through websites such as clinicaltrials.gov	65
From my doctor	56

From companies developing new drugs	38
Not interested in learning about clinical trials	2
	<b>N=167</b>

**11. How important is each of the following factors in deciding whether or not you will participate in a clinical trial, where 1=very unimportant and 5=very important?**

	<b>Average Score</b>
Potential side effects	4.1
Whether will know in advance which treatment group the patient will be in	4.1
Scientific rationale for the clinical trial	4.0
If all participants receive the new treatment	4.0
If some participants in the study are given the current approved treatment and not the new treatment	3.9
Cost of participation in the clinical trial	3.8
How patients who have already participated in the trial feel	3.8
Distance to study center	3.5
How many patients have participated in the trial to date	3.5
Number of visits to the study center	3.3
Type and frequency of monitoring tests	3.3
Length of time spent on each visit to study center	3
	<b>N=164</b>

**12. How likely would you be to need each type of support in order to participate in a clinical trial in which you and the patient would visit the study center regularly, e.g., monthly, where 1 = I would be unlikely to need this, 2 = This would be nice but not necessary, and 3 = I would definitely need this?**

	<b>Average Response</b>
Air travel reimbursement	2.52
Hotel stay reimbursement	2.46
Parking voucher/reimbursement for study center visits	2.11
Reloadable pre-paid debit card for expenses related to study center visit	2.11
Nurse visits to your house or going to a nearby clinic for blood draws and other tests (instead of traveling to the study center)	2.09
Mileage reimbursement for drive to appointments	2.01
Meal vouchers or reimbursement for study center visits	1.90
Reimbursement for taxi or car service to/from appointments	1.88
Reimbursement for public transportation	1.85
Travel agent to arrange travel for your study center visits	1.72

Reimbursement for childcare 1.23  
**N=160**

**13. What is the farthest distance you would be willing to travel every month to participate in a clinical trial?**

Under 25 miles	7%
25-100 miles	26
101-200 miles	9
201-500	10
501-1000 miles	6
1000+ miles away	14
It would depend (please specify factors)	26
	<b>N=164</b>

Among the 43 respondents who mentioned that the distance would depend on factors:

***Cost and availability of financial assistance (47%)***

Go 101-200 miles at my expense, further travels would need reimbursement.

If flights were paid for, I'd participate anywhere.

If expenses were covered, I would travel anywhere.

Depends on flight/hotel cost and how long I'd be away from my family.

If distant, I would need financial assistance for travel.

Around the world if cost is covered.

If I could afford to travel, I would.

\$\$.

Whether expenses for travel were covered.

Cost of flights, hotels, etc. (and reimbursement).

Cost restrictions.

On cost.

Cost of air travel.

If travel is paid.

If travel is compensated, on number of visits needed and if any needed accommodations are compensated. I am on disability so those kinds of expenses are important.

Depends on who's paying to trip, driving about 50 miles, air to pay anywhere.

I currently travel 30 miles. If the trial was out of state but specific for my type of cancer then it would depend on reimbursement.

Costs and what travel might be covered...

On available travel and any needed accommodation reimbursement.

***Potential effectiveness of the treatment (23%)***

If it would save my life, I would find a way!

Would depend on how promising trial seems.

On the trial drug involved and potential outcome of drug.

Depends on whether the drug is a potential life saver.

On the treatment in question.

I wouldn't have a problem traveling for a better treatment.

I will travel within the states. It would have to be VERY promising to consider internationally.

How effective it would be for me.

If the trial was promising I would be willing to have inconvenience. But there is a limit.

If this is promising.

***If clinical trial offers only/best treatment option (9%)***

How necessary the treatment is.  
 I would go anywhere if it is my only choice.  
 If it were my only option, I would travel as far as needed. Otherwise, would prefer options where I could stay w/in Chicago area.  
 If this was my only hope, I would consider any distance.

***Patient's health (9%)***

How I am feeling.  
 On how I am feeling.  
 On progression of my disease and my health.  
 On my health.

***Miscellaneous (21%)***

Drive, up to 200 mi, fly, anywhere.  
 How strong I supported the trial.  
 Time for travel and time away from home.  
 Where.  
 How much I want treatment.  
 If I could drive or if I needed to fly.  
 If I have family or caregiver support who can travel with me if needed.  
 How often I would have to go.  
 All details.

**14. What is your age? (Select one.)**

21-34	4%
35-44	16
45-54	20
55-64	37
65-74	20
75 or older	4
	<b>N=164</b>

**15. What is your gender?**

Male	14%
Female	86
	<b>N = 165</b>

**16. What is your annual household income? (Select one.)**

**Answer Choices**

Less than \$25,000	10%
\$25,000-\$74,999	28
More than \$75,000	49
Prefer not to answer	14
	<b>N = 167</b>

**17. What is the highest level of education you have completed? (Select one.)**

Some high school	0%
High school graduate or GED	10
Some college education	12
Some technical school	1
College graduate	39
Technical school graduate	3
Graduate/professional school	36

**N = 167**

**18. Where do you live? (City, State)**

North Little Rock	AR
Phoenix	AZ
Tucson	AZ
Nanaimo	BC
Bay Area	CA
Fremont	CA
Huntington Beach	CA
Los Angeles	CA
Orange County	CA
San Diego	CA
Colorado Springs	CO
Colorado Springs	CO
Denver	CO
Denver	CO
Dillon	CO
	CT
	CT
Washington	DC
Washington	DC
Millsboro	DE
Fort Myers	FL
Fort Myers	FL
Fort St. Lucie	FL
Ft Myers	FL
Miami	FL

New Port Richey	FL
Pompano Beach	FL
Atlanta	GA
bethlehem	GA
Monroe	GA
St Simons Island	GA
Andover	IL
Chicago	IL
Chicago	IL
Chicago	IL
Highland Park	IL
Joliet	IL
Kankakee	IL
Naperville	IL
Niles	IL
Schaumburg	IL
Southwest	IL
East Chicago	IN
New Haven	IN
Fort Wright	KY
Independence	KY
Louisville	KY
Monroe	LA
Boston	MA
East Walpole	MA
Lowell	MA
Near Boston	MA
Pittsfield	MA
Rockport	MA
Rockport	MA
Baltimore	MD
Bethesda	MD
Bethesda	MD
Bryans Road	MD
Clinton	MD
Manchester	MD
Olney	MD
Silver Spring	MD
Silver Springs	MD
	MD
	MD
	MD
Lewiston	ME
Ann Arbor	MI

Birmingham	MI
Charleston	MI
Charlevoix	MI
Charlevoix	MI
Detroit	MI
East Lansing	MI
Novi	MI
Sterling Heights	MI
Ypsilanti	MI
Elk River	MN
Sauk Center	MN
St. Louis	MO
Canton	MS
Jackson	MS
Kansas City	MS
Ridgeland	MS
walls	MS
Charlotte	NC
High Point	NC
Middlesex	NC
Raleigh	NC
Raleigh	NC
Winston-Salem	NC
Omaha	NE
Omaha	NE
Hampton	NH
Morristown	NJ
Pennsauken	NJ
Henderson	NV
Long Island	NY
Manlius	NY
New Rochelle	NY
New Suffolk	NY
New York	NY
NYC	NY
Rochester	NY
Rochester	NY
rochester	NY
Russell	NY
Rye	NY
Staten Island	NY
Syracuse	NY
	NY
Cleveland	OH

Columbus	OH
Columbus	OH
Kent	OH
Pioneer	OH
Pioneer	OH
Toledo	OH
Willowick	OH
Woodville	OH
	OH
Grove	OK
Moore	OK
Eugene	OR
Portland	OR
POrtland	OR
Woodburn	OR
Broomall	PA
Connellsville	PA
Lancaster	PA
Langhorne	PA
Philadelphia	PA
Pittsburgh	PA
Stewartstown	PA
	RI
Memphis	TN
Memphis	TN
Nashville	TN
Austin	TX
Dallas	TX
Hurst	TX
Irving	TX
North Richland Hills	TX
Rockwall	TX
Aldie	VA
Alexandria	VA
Arlington	VA
Arlington	VA
Briston	VA
Fairfax	VA
Harrisonburg	VA
Haymarket	VA
Herndon	VA
McLean	VA
Richmond	VA
Springfield	VA

Williamsburg	VA
	VA
Kirkland	WA
Port Orchard	WA
Seattle	WA
Neenah	WI

## **Caregiver Survey (Observations and Tabulated Data)**

## **Observations from 2017 Clinical Trial Caregiver Survey**

**N = 49**

### **Snapshot of the caregiver respondents**

Forty-nine caregivers responded to the clinical trial survey. The sample size is high enough that the responses fairly represent *this* group, which may not represent all caregivers. This group differs from the general US population in that it:

- is more highly educated than the general US population: about 60% completion of college and/or graduate school vs. 32%
- has a higher income than the general US population: 58% reported household income of more than \$75,000 vs. 28%

It is reasonable to assume that this group, by their higher socioeconomic level and by their attendance along with their patients at a LUNGevity HOPE Summit or their willingness to take an online survey, is a relatively more engaged and informed group than other lung cancer caregivers. The reported level of openness of their patients to clinical trial participation probably represents the highest level that would be observed among all lung cancer caregivers.

### **Snapshot of the patients receiving care**

The majority of the patients (88%) whom these caregivers tend to have a diagnosis of non-small cell lung cancer, which matches closely the 85% of the general lung cancer community.

Not surprisingly, by far the most caregivers (84%) provide support to those patients most likely to need care, those with stage IV/advanced-stage/metastatic lung cancer.

Caregivers reported that 85% of the patients receiving care have had their tumors tested for biomarkers. This rate is considerably higher than in the general lung cancer population where testing rates of 65%-70% are reported.

Among those patients whose tumors have been profiled, more have been tested for EGFR, ALK, KRAS, and PD-L1 than for other biomarkers; except for KRAS, these biomarkers are all currently targetable or are used for patient selection for treatment. Around 7%-14% of the caregivers reported that their patients have had their tumors tested for the rarer driver mutations in adenocarcinoma (ROS1, BRAF, EGFR, HER2, MET, NRTK, and RET). The majority of the 28% of those caregivers who are not sure for which biomarkers their patient were tested are caring for patients who have not been on a targeted therapy so most likely tested negative for any biomarkers.

Seventy-six percent of their patients who have had biomarker testing were tested before any treatment started. Fewer than 20% of the caregivers reported that their patient's tumor was profiled at the time of recurrence after first- and second-line therapy.

Among the different treatment approaches, chemotherapy (71%) and radiation therapy (60%) are the most common ones received by patients. Fifty-six percent of the patients have received targeted therapy. Seventy-one percent of the patients have received more than one type of treatment.

### **Caregiver role in decision-making about clinical trials**

Among the 49 caregivers who responded to the survey, only 15% claim to have no role in the patient's decision-making about clinical trials. Given their influence in decision-making, there is a need for developing caregiver-focused education about clinical trials.

### **Desired sources of information about clinical trials**

When asked about how they and the patient would like to receive information about clinical trials, no matter what other sources of information they would like to have, almost all of caregivers (90%) would like to receive information regarding clinical trials directly from the patient's doctor. Other sources of interest are patient advocacy groups (48%) and websites such as [clinicaltrials.gov](http://clinicaltrials.gov) (33%). Only 19% would like to receive information from companies developing new drugs.

### **Clinical trial past and future participation rates**

Of the patients being cared for, about 40% have previously participated in a clinical trial. The reported participation rate is higher than the rates reported (3%-5%) in the overall cancer patient community, reinforcing that these caregivers and their patients represent a more engaged population.

Seventy-five percent of caregivers reported that their patient would consider participating in a clinical trial. Almost all of the other caregivers reported that they are unsure whether their patient would consider participating in a clinical trial rather than reporting a definite "no." Again, this percentage is probably the maximum response possible among the entire lung cancer patient community.

### **Reasons for clinical trial participation**

Among the 20 caregivers who provided their own reasons why their patients would consider participating in a future clinical trial, there are two categories of response: access to treatment options and helping others/science. Access to treatment options reasons were named more often (samples of responses are included):

#### ***Access to treatment options***

If needed. Currently stable. Would try anything.

Looking for silver bullet

Plan C if necessary

It's the cutting edge of treatment and we might not have other options or want to avoid chemo

My husband is not afraid to try clinical trials. It's what kept him alive the last 6 years.

He feels clinical trials are the best chances for continued survivorship.

If current treatment isn't working I would consider clinical trial

To live longer when out of good treatment options

Her drugs cost too much and can't afford them

#### ***Altruism/Advancement of science***

To help self and progress science

We have chance to help others

Because it could help someone else even if it doesn't help him

Willing to advance science and hope to find cure

To help continue research in to lung cancer.

To contribute to the knowledge. Tools to help himself

Among the six caregivers who provided their own reasons why they are not sure whether their patient would consider participating in a future clinical trial, the barriers to participation are varied:

***Barriers to participation***

She is very uncomfortable with changing treatment options

Patient is 84 years old

She's in hospice.

Diagnosed with cancer 2010 treated and still ok to date.

In hospice seeking quality of life

Her current treatment is working well (Tagrisso). If it gets to the point where her meds are not working, she may do clinical trials.

In addition to offering their own reasons for a patient's participation or not in a clinical trial, caregivers were provided a list of 13 factors that could help a patient decide whether to participate in a clinical trial. The factors that more caregivers are likely to assign a higher importance score relate to how the clinical trial might affect the patient:

- Potential side effects
- Whether will know in advance which treatment group patient will be in
- The scientific rationale for the clinical trial
- If all participants receive the new treatment

Caregivers were least likely to assign a higher score to logistical factors:

- Distance to study center
- Number of visits to the study center
- Length of time spent on each visit to study center
- Type and frequency of monitoring tests

Educational materials about a clinical trial need to include both types of information.

**Type of support likely to be needed in order to participate in a clinical trial**

Caregivers were presented with a list of types of support and assessed each for the likelihood of it being needed in order to participate in a clinical trial in which the patient and caregiver would visit the study center regularly. While at the very top of their list are financial reimbursement for airfare and for hotel accommodations, also relatively high on support needs are nurse visits to the patient's house or driving to a nearby clinic for blood draws and other tests instead of traveling to the study center. These caregivers are indicating a willingness to travel but a desire to not always have to do so.

**Distance willing to travel to participate in a clinical trial**

There is no trend in the distance that caregivers and the patients would be willing to travel every month to participate in a clinical trial; 25-100 miles and 501-1,000 miles were the ranges selected most often as the farthest distance; 19% of caregivers selected each of those ranges. However, 31% did not select a range at all but said that how far they would travel would depend. Among the 13 caregivers who specified a factor, the availability of financial assistance is the single factor most often named.

## 2017 Clinical Trial Caregiver Survey Tabulations

In summer of 2017, LUNGevity Foundation surveyed caregivers to lung cancer patients about participation in clinical trials. A total of 49 caregivers (31 in-person respondents at the National HOPE Summit and 18 online respondents) responded to the survey.

Response percentages are based on the number of respondents who answered each question.

### 1. What type of lung cancer does the patient have? (Select one.)

Non-small cell lung cancer (NSCLC): Adenocarcinoma	67%
Non-small cell lung cancer (NSCLC): Squamous cell lung	15
Non-small cell lung cancer (NSCLC): Type unspecified	6
Carcinoid or neuroendocrine tumor	4
Other (please specify)	4
Small cell lung cancer (SCLC)	2
Not sure	2
Non-small cell lung cancer (NSCLC): Large cell lung cancer	0
	<b>N = 48</b>

### 2. Which stage best describes the stage of the patient's disease? (Select one.)

Stage IV/Advanced-stage NSCLC	69%
Metastatic NSCLC	15
Stage III NSCLC	8
Other (please specify)	4
Stage I NSCLC	2
Extensive Stage SCLC	2
Stage II NSCLC	0
Limited Stage SCLC	0
Not sure	0
	<b>N = 48</b>

### 3. Was the patient's tumor tested for biomarkers? In biomarker testing (also known as molecular or tumor testing), the doctor removes a small piece of cancer tissue through a biopsy and sends it to a pathology laboratory for testing. Presence or absence of specific biomarkers may help guide treatment decisions, such as use of targeted therapy or immunotherapy. (Select one.)

Yes	85%
No	10
Not sure	5
	<b>N = 48</b>

**4. For what biomarkers was the patient’s tumor tested? (Select all that apply. Please skip if you have responded NO to question 3.)**

EGFR	51%
ALK	40
Not sure	28
KRAS	21
PD-L1	21
BRAF	14
MET	14
RET	14
HER2	12
ROS	9
NTRK	7
Other (please specify)	0
<b>N = 41</b>	

**5. When was testing performed? Select all that apply. (Please skip if you have responded NO to question 3.)**

Before treatment was started	80%
After initial treatment was started, because the cancer came back	17
After initial treatment: unspecified	12
After initial treatment, because new markers known/new treatment available	5
After second treatment was started, because the cancer came back	1
Not sure	0
<b>N = 41</b>	

**Other responses include:**

ALK and EGFR at time of diagnosis, PD-L1 after treatment because FDA approved Keytruda for NSCLC  
 Multiple times as new markers came out  
 2 times at diagnosis, 3rd time to get on a trial, none successful  
 Post surgery  
 With treatment  
 After initial treatment, saw a general oncologist I had to prompt  
 After neoadjuvant treatment/post-op

**6. What treatment(s) has the patient ever received (either currently or in the past) for lung cancer? (Select all that apply.)**

Chemotherapy	71%
Radiation therapy	60
Targeted drug therapy (drug that attacks a specific mutation, e.g., Tarceva)	56
Immunotherapy (drug that helps the body recognize and fight the lung cancer, e.g., Opdivo)	31
Palliative care (treatment of symptoms of lung cancer or side effects of treatment)	25
Surgery	21
Angiogenesis inhibitor (drug that stops the growth of new blood vessels that feed the tumor, e.g., Avastin)	10
Not sure	2
Other (please specify)	2
	<b>N=48</b>

**7. Which decision-making role about the patient’s participation in clinical trials best describes you? (Select one.)**

I have some influence over decisions about participation in a clinical trial	38%
I have a major influence over decisions about participation in a clinical trial	29
I am the primary decision maker about participation in a clinical trial	17
I do not make or influence decisions about participation in a clinical trial	15
	<b>N = 47</b>

**8. Has the patient ever participated in a clinical trial of a new drug for his/her type of lung cancer? (Select one.)**

No	55%
Yes	39
Not sure	6
	<b>N=47</b>

**9. Would the patient consider participating in a future clinical trial of a new drug for his/her type of lung cancer? (Select one.)**

Yes	75%
No	4
Not sure	21

**When asked for reasons, among those who responded:**

**Among those who answered YES (N=20)**

***Access to treatment options***

- If needed. Currently stable. Would try anything.
- Looking for silver bullet
- If required
- Because it might help
- Plan C if necessary
- It's the cutting edge of treatment and we might not have other options or want to avoid chemo
- My husband is not afraid to try clinical trials. It's what kept him alive the last 6 years.
- He feels clinical trials are the best chances for continued survivorship.
- If current treatment isn't working I would consider clinical trial
- To live longer when out of good treatment options
- It may help
- Always a risk taker
- He wants to fight this and wants to live
- Her drugs cost too much and can't afford them

***Altruism/Advancement of science***

- To help self and progress science
- We have chance to help others
- Because it could help someone else even if it doesn't help him
- Willing to advance science and hope to find cure
- To help continue research in to lung cancer.
- To contribute to the knowledge. Tools to help himself

**Among those who answered NOT SURE (N=6)**

***Barriers to participation***

- She is very uncomfortable with changing treatment options
- Patient is 84 years old
- She's in hospice.
- Diagnosed with Cancer 2010 treated and still ok to date.
- On hospice seeking quality of life
- Her current treatment is working well (Tagrisso). If it gets to the point where her meds are not working, she may do clinical trials.

**Among those who answered NO (N=1)**

***Miscellaneous***

- Died 11/16

**10. How would you and the patient like to receive information about clinical trials? (Select all that apply.)**

From the patient's doctor	90%
From patient advocacy groups (e.g. LUNGEvity)	48
Online through websites such as clinicaltrials.gov	33
Not interested in learning about clinical trials	21
From companies developing new drugs	19
Other (please specify)	2
	<b>N = 48</b>

Others: Mail or text

**11. How important is each of the following factors in deciding whether or not the patient will participate in a clinical trial, where 1 = very unimportant and 5 = very important? (Circle one number for each factor.)**

	<b>Average Score</b>
Potential side effects	4.1
Whether will know in advance which treatment group I will be in	4.1
Scientific rationale for the clinical trial	4.0
If all participants receive the new treatment	4.0
If some participants in the study are given the current approved treatment and not the new treatment	3.9
How patients who have already participated in the trial feel	3.8
Cost of participation in the clinical trial	3.7
How many patients have participated in the trial to date	3.6
Distance to study center	3.3
Number of visits to the study center	3.0
Length of time spent on each visit to study center	2.8
Type and frequency of monitoring tests	2.8
	<b>N=47</b>

**12. How likely would you be to need each type of support in order to participate in a clinical trial in which you and the patient would visit the study center regularly, e.g., monthly, where 1 = I would be unlikely to need this, 2 = This would be nice but not necessary, and 3 = I would definitely need this? (Circle one number for each factor.)**

	<b>Average Score</b>
Air travel reimbursement	2.3
Hotel stay reimbursement	2.2
Parking voucher/reimbursement for study center visits	2.0
Nurse visits to the patient's house or going to a nearby clinic for blood draws and other tests (instead of traveling to the study center)	2.0
Mileage reimbursement for drive to appointments	1.9
Reimbursement for public transportation	1.9
Reimbursement for taxi or car service to/from appointments	1.8
Reloadable pre-paid debit card for expenses related to study center visit	1.8
Meal vouchers or reimbursement for study center visits	1.7
Travel agent to arrange travel for your study center visits	1.7
Reimbursement for childcare	1.2
	<b>N=45</b>

**13. What is the farthest distance you and the patient would be willing to travel every month to participate in a clinical trial? (Select one.)**

Under 25 miles	7%
25-100 miles	19%
101-200 miles	10%
201-500	7%
501-1000 miles	19%
1000+ miles away	7%
It would depend (please specify factors)	31%
	<b>N=42</b>

Among the 13 caregivers who specified that the distance would depend, the factors are:

**Availability of financial assistance (N =6)**

Available reimbursements or covered costs of travel and any needed accommodations.

Can we afford to fly there?

Expense

How much money I would have to pay

Assistance possibilities

Financial assistance

**Availability of other treatment options (N=3)**

Depends on if we have other options, or if he's at the last options, if so, we'd go anywhere

Type of tx/other contributing factors

How patient is currently feeling. Other available options?

**Location of the trial (N=2)**

On where the trial was  
Any distance

**Miscellaneous (N=2)**

Will travel if necessary  
I am from Mongolia

**14. What is your age? (Select one.)**

21-34	16%
35-44	16
45-54	16
55-64	38
65-74	13
75 or older	2

**N = 45**

**15. What is your gender?**

Male	25
Female	75

**N = 44**

**16. What is your annual household income? (Select one.)**

Less than \$25,000	11
\$25,000-\$74,999	20
More than \$75,000	58
Prefer not to answer	11

**N = 45**

**17. What is the highest level of education you have completed? (Select one.)**

Some high school	2%
High school graduate or GED	7
Some college education	25
Some technical school	2
College graduate	34
Technical school graduate	5
Graduate/professional school	25

**N = 44**

**18. Where do you live? (State, City)**

Peoria	AZ
Phoenix	AZ
Hemet	CA
Sacramento	CA
Hemet	CA
Storrs	CT
Danbury	CT
Hudson	FL
Melbourne	FL
Fort Myers	FL
Algonquin	IL
East Chicago	IN
Monroe	LA
Boston	MA
Burstonsville	MD
Manchester	MD
Burton	MI
Detroit	MI
Ann Arbor	MI
Novi	MI
Eagan	MN
Kansas City	MO
Canton	MS
	NC
Omaha	NE
	NV
Patchogue	NY
Russell	NY
Syracuse	NY
Napoleon	OH
Pioneer	OH
Woodville	OH
Pittsburgh	PA
Nashville	TN
Memphis	TN
Plano	TX
DFW	TX
Bridgewater	VA
Williamsburg	VA
Puyallup	WA

Seattle	WA
Neenah	WI
Ulaanbaatar	Mongolia
Bristol	UK