



LUNGEVITY

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REACHING THE UNREACHED
RESULTS OF A PILOT STUDY

DECEMBER 2016



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INTRODUCTION TO PROJECT

PURPOSE OF PILOT STUDY

To get a feel for how patients and caregivers who are reached—those who are engaged with the lung cancer community and have relatively easy access to information—get their information about the patient’s lung cancer and how they would prefer to get it

To determine what barriers to getting the information they perceive as well as what information they do not feel that they are getting

To understand the physician perspective on barriers to relaying information and solutions to these barriers

To use the findings of this study to help design a full-scale study among those patients and caregivers who are not as reached as the respondents of this study

HOW THE SURVEYS WERE CONDUCTED

Patients

- Survey Monkey survey deployed through LUNGeivity social media
- Survey fielded at lung cancer survivorship conference
- 116 respondents

Caregivers

- Survey Monkey survey deployed through LUNGeivity social media
- Survey fielded at lung cancer survivorship conference
- 40 respondents

Physicians

- Survey emailed to LUNGeivity clinicians (Scientific Advisory Board members and awardees)
- 19 respondents



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PATIENT AND CAREGIVER RESULTS

MAJOR OBSERVATIONS ABOUT HOW PATIENTS AND CAREGIVERS GET THEIR INFORMATION ABOUT LUNG CANCER

1. Patients and caregivers have similar habits and attitudes about seeking information about lung cancer
2. Patients and caregivers get information from multiple sources, including from multiple members of the medical team.
3. The oncologist and lung cancer organizations are by far the preferred sources.
4. When given a choice, poking around on the internet and using social media go down in importance and print materials go up, although print materials are still less important.
5. Lack of community resources was a major barrier for patients and caregivers who cited a barrier.
6. Because information is received throughout the treatment journey, Information given to patients and caregivers should be customized to each point in the treatment journey.
7. Patients and caregivers like information that is tailored to their own situations.

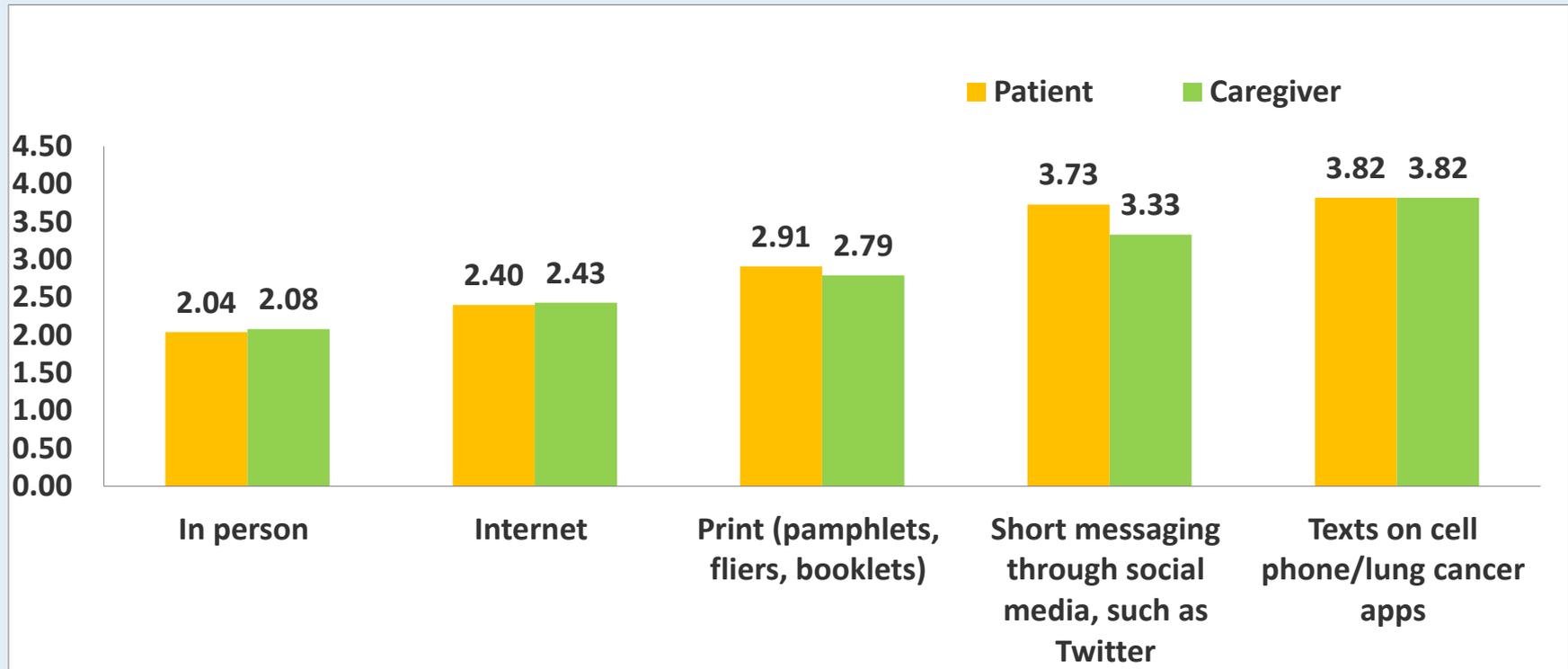
PATIENT-IDENTIFIED CURRENT AND PREFERRED SOURCES OF INFORMATION (MULTIPLE CHOICES ALLOWED)

SOURCE OF INFORMATION	CURRENT SOURCE (N = 112)	PREFERRED SOURCE (N = 112)
Lung cancer organizations/PAGs	83%	77%
Patient's doctor: oncologist	73%	80%
Internet searches	66%	38%
Facebook or other social media	56%	38%
Newspaper articles or radio/television news stories	25%	21%
Patient's nurse practitioner/physician's assistant	22%	20%
Family member or friend	18%	10%
Patient's doctor: pulmonologist	17%	21%
Patient's doctor: PCP	16%	24%
Brochures/mailings from clinics	14%	23%
Other member of the healthcare team	10%	6%
Patient's social worker	6%	8%
Texts on cell phone/lung cancer apps	1%	11%

CAREGIVER-IDENTIFIED CURRENT AND PREFERRED SOURCES OF INFORMATION (MULTIPLE CHOICES ALLOWED)

SOURCE OF INFORMATION	CURRENT SOURCE (N=40)	PREFERRED SOURCE (N=40)
Patient's doctor: oncologist	85%	76%
Internet searches	73%	51%
Lung cancer organizations/support groups/patient advocacy groups	58%	73%
Patient's doctor: primary care physician	35%	42%
Patient's nurse practitioner/physician's assistant	25%	32%
Facebook or other social media	25%	17%
Family member or friend	23%	15%
Newspaper articles or radio/television news stories	23%	22%
Patient's doctor: pulmonologist	10%	17%
Patient's social worker	10%	5%
Brochures or mailings from hospitals, clinics, or doctors' offices	5%	27%
Texts on cell phone/lung cancer apps	5%	12%
Other member of the healthcare team	5%	7%

PATIENT AND CAREGIVER-IDENTIFIED PREFERRED FORMAT OF RECEIVING INFORMATION ON LUNG CANCER



On a scale of 1 to 5, where:
1 = Most Preferred
5 = Least Preferred

38% PATIENTS/ 45% CAREGIVERS CITED MAJOR BARRIERS IN ACCESSING INFORMATION

BARRIER	PATIENT (N=44)	CAREGIVER (N=18)
I don't understand what the doctor is telling me or the patient because s/he goes too fast or uses technical words	18%	39%
Few local community resources	43%	33%
Not sure where to find information	25%	16%
Healthcare coverage	5%	11%
Challenges getting hold of medical professionals	25%	11%
Limited access to the Internet or a computer	3%	0%
My primary language is not the same as that of the patient's healthcare team	9%	6%

7% PATIENTS/6% CAREGIVERS CITED “OTHER” BARRIERS TO ACCESSING INFORMATION

Information about disease

- Differing opinions of standard of care.
- Understanding med terms and seeing all options
- I get information, but I feel I need to work hard for it, rather than my health team providing it to me.
- No information out there .unless you go to a cancer center. Or internet
- I believe we can get information on Lung Cancer, but we don't know what we don't know... What is out there we don't know about?
- **I don't know if I am getting ALL the information I need (CAREGIVER)**

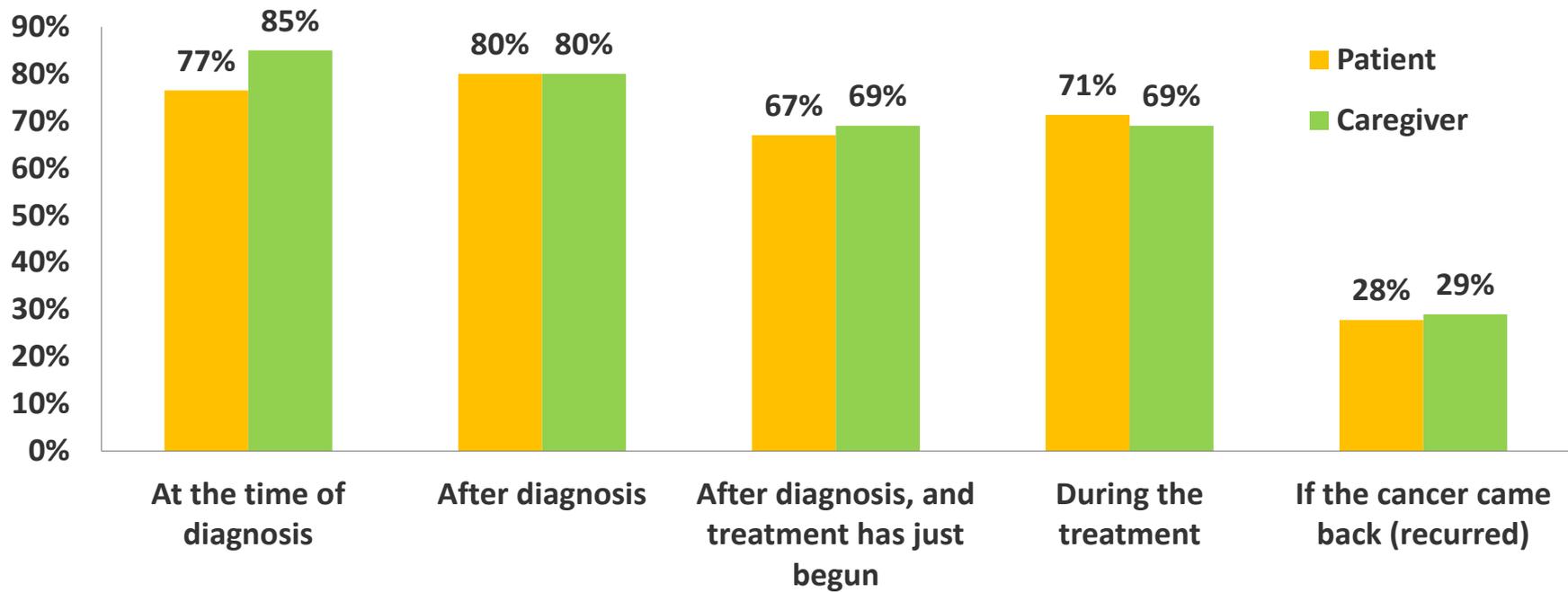
Physician attitude and communication

- I feel my doctor is hesitant to be too hopeful, yet hesitant to be too truthful. Therefore, I find myself on NIH and other Cancer sites, which is where it was recommended I not spend too much time on.
- **I feel the doctors keep everything professional and don't connect on a personal, specific case level (CAREGIVER).**

Lack of resources to access education

I live in the middle of cornfields and no where to go , no support groups

PATIENTS AND CAREGIVERS RECEIVE INFORMATION AT ALL POINTS OF THE LUNG CANCER JOURNEY





PHYSICIAN PERCEPTIONS ABOUT RELAYING INFORMATION

MAJOR OBSERVATIONS ABOUT PHYSICIAN-PERCEIVED BARRIERS TO RELAYING INFORMATION AND SUGGESTIONS ABOUT REMOVING BARRIERS

1. The physicians cited a number of barriers: lack of time to speak with patients and poor understanding by the patients (this is separate from English not being the patient's first language) are the barriers mentioned most often.
2. While inadequate educational materials were cited by only 11% of the physicians, most of their suggestions about removing barriers focused on improving the content of and channels for relaying information (suggesting that doctors don't have the answers to the two most cited barriers, either)
3. About one-fifth of the physicians in our sample, most of whom work in major urban centers, cited patients not being English speakers as a problem. There is a clear need for translators as well as materials being available in other languages, Spanish and Chinese in particular.

MAJOR PHYSICIAN BARRIERS/CHALLENGES IN RELAYING INFORMATION TO PATIENTS OR CAREGIVERS

Lack of time (32%)

1. Limited time with patient
2. Time that I can spend in clinic...to educate patient/caregiver
3. Limited time during consultations and follow-up visits
4. Insufficient time in clinic to teach patients the basics

Poor understanding by patient (26%)

1. Misconceptions about lung cancer and its treatment, especially about chemotherapy
2. Lack of understanding by patient that treatment does not equal cure but will most likely prolong and improve quality of life

Patient not English speaker (21%)

1. Language barrier
2. Lack of effective communication with minority, underserved communities, especially Hispanic and Chinese
3. Foreign language speaker

Patient fear/stress (16%)

1. Fear prevents understanding of medical lingo
2. Fear of toxicity, so some patients refuse treatment
3. Stress leads to poor understanding/retention

Inadequate educational materials (11%)

1. Current printed info and websites are not adequate
2. Lack of concise, easily understood handouts, especially regarding treatment plan

Problems with medical practitioners (11%)

1. Lack of awareness of treatments among primary care physicians
2. Pessimism among medical practitioners limits patient access to good information and treatment options

Other (26%)

1. Loved ones not always present
2. Access to doctors after the visit
3. Trust
4. Technological barriers
5. Hard to tailor information exactly to patient needs

PHYSICIAN SUGGESTIONS FOR REMOVING THESE BARRIERS

Better education in general (53%)

1. More simple language
2. Better education about treatment advances
3. Materials with diagrams and illustrations over plain text
4. Take patients through a question-based sequential workflow.
5. Patient should be led to answers that they need, not to generalized database or to get too much information at once.
6. FAQ page, something like Things I wish I knew before I started treatment...
7. More vigorous denunciation of fraudulent remedies
8. Patient-friendly diagrams with images and photos
9. Sketch a decision flowchart for each patient
10. Allow patients to record doctors

Better printed materials (42%)

1. Communication booklets detailing treatment options and explanations
2. Good printed information
3. Pdf files that can be printed from Internet and handed to patients
4. Patient handouts that are patient- and context-specific
5. Handouts at different stages of the disease
6. Schematic reporting, e.g., patient clinical management sheet
7. Easy to understand brochures specific to the treatment of lung cancer
8. Better written information about likelihood of side effects

Forms of communication other than websites and printed materials (32%)

1. Blogs
2. Newsletters
3. Social media campaigns
4. Centralized smart phone or iPad accessible application
5. More blogs/Facebook videos to explain different aspects of lung cancer care
6. More video resources of patients who have been through various treatments/steps

PHYSICIAN SUGGESTIONS FOR REMOVING THESE BARRIERS (CONT'D.)

Websites (26%)

1. Website detailing treatment options and explanations
2. Website for patients that shows what a lung cancer is, how it spreads, and what it can do
3. Visual explanation best
4. Website for primary care physicians and other physicians about lung cancer treatment
5. Plainspoken website or app that is easy to get to, show up highly on search engines, and not overload the reader
6. Good website in which I have confidence

Help for non-English speakers (26%)

1. In-person translator during initial consult
2. Support group or go-to person/navigator in multiple languages and cultures
3. Good printed information and web-based information in their own language
4. Materials in common languages outside English; presume Spanish and Chinese most pressing
5. Materials in common languages, e.g., Spanish
6. Culturally sensitive medically competent bilingual translators

Other (26%)

1. Patients meeting with whole medical team
2. More support groups
3. More patient navigators in the clinic
4. More patient voices to destigmatize lung cancer
5. Patient navigators and social workers—live person resources—do a better job than materials in conveying practical information



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RESPONDENT PROFILE

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AGE

	Patients (N=116) %	Caregivers (N=39) %
0-50	25%	40%
51-67	65%	53%
68 and above	10%	7%

LANGUAGE FOR INFORMATION

**99% respondents prefer to receive information
in English**

The average age at a lung cancer diagnosis is 70. Our self-selected sample has a much younger profile. This contributes to our understanding of who the “unreached” might include: it appears that older patients/caregivers are not engaging with the lung cancer community via social media. Likewise, people whose first language is not English will not likely be reached by English social media.

RESPONDENT PROFILE

EDUCATION LEVEL

	Patients (N=116) %	Caregivers (N=39) %
Some High School	1%	3%
High School or GED	13%	5%
Some College Education	19%	18%
Some Technical Education	1%	0%
College Graduate	39%	49%
Technical School Graduate	4%	8%
Graduate/ Professional School	23%	18%

INCOME

	Patients (N=116) %	Caregivers (N=39) %
Less than \$25,000	6.3%	10%
Between 25,000-\$74,999	37%	39%
More than \$75,000	36%	33%
Prefer not to answer	21%	18%

GENDER

	Patients (N=116) %	Caregivers (N=39) %
Male	11%	24%
Female	89%	76%

RESPONDENT PROFILE – LUNG CANCER INFORMATION

Location of lung cancer at time of diagnosis

	Patients (N=116) %	Caregivers (N=40) %
One lung	80%	71%
Lymph node(s)	35%	32%
Bone	24%	24%
Pleura	14%	20%
Both lungs	16%	17%
Brain	15%	10%
Liver	6%	7%
I don't know	0%	2%
Other	8%	20%

Type of treatment received

	Patients (N=116) %	Caregivers (N=40) %
Chemotherapy	62%	65%
Radiation therapy	54%	65%
Targeted drug therapy	52%	43%
Surgery	53%	33%
Palliative care	16%	20%
Immunotherapy	9%	20%
Angiogenesis inhibitor	11%	18%
None of the above	1%	8%
Other (please specify)	6%	8%
I don't know	1%	0%

RESPONDENT PROFILE – LUNG CANCER INFORMATION (CONTINUED)

Stage of Diagnosis of lung cancer		
	Patients (N=116) %	Caregivers (N=40) %
Stage IV	49%	66%
Stage III	22%	17%
Stage I	15%	7%
Stage II	11%	5%
Limited-Stage Small Cell Lung Cancer	0%	5%
Extensive-Stage Small Cell Lung Cancer	3%	0%
I don't know	1%	0%

Histology of lung cancer		
	Patients (N=116) %	Caregivers (N=40) %
Non-small cell lung cancer (NSCLC): Adenocarcinoma	76%	51%
Non-small cell lung cancer (NSCLC): Squamous cell lung cancer	6%	22%
Non-small cell lung cancer (NSCLC): type unspecified	7%	10%
Small cell lung cancer (SCLC)	3%	10%
Non-small cell lung cancer (NSCLC): Large cell lung cancer	2%	2%
I don't know	2%	2%
Other (please specify)	0%	2%



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TO SUMMARIZE:

To get a feel for how engaged patients and caregivers get their information about the patient's lung cancer and how they would prefer to get it

- Patients and caregivers have similar habits and attitudes about seeking information about lung cancer
- Patients and caregivers get information from multiple sources, including from multiple members of the medical team.
- The oncologist and lung cancer organizations are by far the preferred sources.
- When given a choice, poking around on the internet and using social media go down in importance and print materials go up, although print materials are still less important.

To determine what barriers to getting the information they perceive as well as what information they do not feel that they are getting

- Lack of community resources was a major barrier for patients and caregivers.
- Because information is received throughout the treatment journey, Information given to patients and caregivers should be customized to each point in the treatment journey.
- Patients and caregivers like information that is tailored to their own situations.

To understand the physician perspective on barriers to relaying information and solutions to these barriers

- The physicians cited a number of barriers: lack of time to speak with patients and poor understanding by the patients (this is separate from English not being the patient's first language) are the barriers mentioned most often.
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- About one-fifth of the physicians in our sample, most of whom work in major urban centers, cited patients not being English speakers as a problem. There is a clear need for translators as well as materials being available in other languages, Spanish and Chinese in particular.

To use the findings of this study to help design a full-scale study among those patients and caregivers who are not as reached as the respondents of this study

- Include specific unreached groups of lung cancer patients and caregivers (linguistically isolated, geographically isolated, financially isolated, etc.)
- Online and paper surveys are unlikely to yield the necessary information—personal interviews and/or focus groups might be better ways to go
- Dig deeper into perceived barriers and potential solutions
- Determine what educational materials work best and why
- Ask patients and caregivers about whether they want graduated information to be given as the treatment journey progresses