



Reaching the Unreached: HCP Attitudes on and Usage of Patient Education Materials

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ABOUT LUNGevity

LUNGevity, the nation's premier lung cancer-focused non-profit, is dedicated to changing outcomes for people with lung cancer through research, education, and support.

We focus on research because the link between research spending and improved survival is clear. Survival rates have dramatically improved for colorectal, breast, and prostate cancers over the last several decades in step with the exponential growth in their research spending. Our goal is to accelerate progress for lung cancer in the same way, in order to dramatically improve on the current 18% five-year survival rate.

LUNGevity research investments focus on:

- Early detection—survival rates rise when lung cancer is detected while still localized
- More effective treatment approaches—getting the right treatment to the right patient at the right time to help people with lung cancer live longer and better

Through our Patient FoRCe Research Center, a bridge to connect the patient voice with healthcare professionals, regulators, policymakers, and developers of drugs, we focus on both qualitative and quantitative research to uncover gaps in information, misperceptions about patient attitudes, and areas of unmet need. We then incorporate the lung cancer patients' preferences and experiences into the development of relevant policy, treatments, and research protocols.

LUNGevity also provides a community of empowerment, support, and hope for everyone affected by lung cancer through our extensive educational resources, online peer-to-peer support, and in-person survivorship programs, as well as more than 80 grassroots awareness and fundraising events held from coast to coast each year.

For more information visit us at www.LUNGevity.org.

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EXECUTIVE SUMMARY

Background: Health outcomes improve when patients are educated about their disease and can engage in shared decision-making with their healthcare provider (HCP).¹⁻³ LUNGeVity has conducted two research studies about the educational needs of patients:

- An initial study among patients and caregivers to find out what information they want, when they want it, and in what format they want it. The results indicated that patients and their caregivers do not believe that they always receive the materials they need, affecting their ability to make the best decisions about their care and treatment.
- A larger, second study, the results of which are the focus of this report, among HCPs to determine their patient education attitudes and practices, as well as the barriers to distributing materials and possible solutions.

Results and Implications: Among the 216 HCPs surveyed:

Findings	Implications
While HCPs do want informed and engaged patients, this sentiment is not without reservation. Eighty-seven percent of HCPs surveyed report the importance of treating an informed patient. However, qualitative feedback underscored concerns measured in the survey over quality, accuracy, and realistic portrayals of treatment scenarios and options.	<i>It is not that physicians and others are discouraging patients from accessing information; but HCPs want to channel patients to information that is accurate, clear, and helpful.</i>
The most significant barriers to disseminating information are specificity to a patient’s diagnosis, accuracy, time, and clarity of scientific explanations. HCPs want patients to understand what is most likely going to be the outcome of their treatment, not necessarily every possibility available.	<i>Being able to customize information to patients’ situations would be welcome. An end-to-end source that can be accessed as needed would be welcome. Interestingly, patients and their caregivers also highlighted the importance of customized information – precise information about precision medicine!</i>
Practically speaking, dissemination practices vary widely, are often based on the HCP’s judgment and the patient’s status. This makes for inconsistent delivery of education materials.	<i>The main hurdle is how to get the right information to the patient at the right time and in a way that allows for discussion. Delivery prior to the appointment was suggested as a possible best practice.</i>
Further, there is typically no point person for materials curation and review; and most report cobbling together information from many sources. There is interest in a reviewed, vetted source.	<i>This suggests that even within a point of care, there may be no common sources or referrals going to all patients. It may also indicate more traction for a go-to source if one can be created.</i>
There is interest and desire for digital information sources, but HCPs still feel printed resources (59%	<i>It is easy for information to be out of date, making the case for web-based sources, but equally important to</i>

prefer printed over other mediums) allow them to engage the patients more effectively and get information to a patient that allows them to understand it in their own time

get something tangible in the hands of patients. Printable content would be valued. However, it is important to note that just handing over print materials is not sufficient and should not be considered shared decision making.¹⁴

Potential solutions offered: Distribution practices for educational materials are not standard and tend to be subject to the HCP's own discretion, leading to inconsistent delivery of materials. In-depth interviews with HCPs suggest several possible solutions, including customization to a patient/caregiver's unique type of lung cancer, availability of multiple formats of education materials for distribution, and white labeling of materials to allow re-branding to an HCP's unique practice setting. Because HCPs know what they want from educational materials, there would be a powerful benefit to consulting with HCPs while materials are being developed. Materials that meet the HCPs' needs are more likely to make it to patients. In addition, our study identified gaps in the dissemination of patient education. Having a designated person in the HCP's office who is in charge of review and material distribution would help alleviate this issue.

INTRODUCTION

The landscape of lung cancer treatment is changing rapidly; in the last two years alone, there have been 12 new treatment approaches approved for the treatment of non-small cell lung cancer (NSCLC).⁴⁻⁶ While these treatments bring new hope, they can also make understanding a lung cancer diagnosis and making the best treatment decisions about customized care a challenge for both patients and caregivers. In addition, lung cancer is a highly heterogeneous disease. NSCLC and small cell lung cancer (SCLC) are the two main subtypes of lung cancer.⁷ Each subtype is further divided into smaller subsets based on the unique molecular biology of the disease.⁴ The complexity of the disease makes it even more important to ensure that patients and their caregivers have access to the right type of information at the right point of the treatment journey (at diagnosis, before starting treatment, during treatment, and at progression or recurrence).

Research has repeatedly confirmed the importance of patient education:⁸

- Patients who feel more informed about their health also feel more confident about their ability to make healthcare decisions
- Choice over treatment alternatives enhances outcomes for patients. Shared decision-making about treatment decisions in which a patient is a partner in their healthcare choices improves outcomes⁹

In 2016, LUNGevity fielded a survey-based study to understand whether lung cancer patients and their caregivers receive adequate information about their treatment options at different points of their treatment journey.¹⁰ The study demonstrated that patients and their caregivers have similar education needs. In addition, they 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.

This study made it clear that because information is received throughout the treatment journey, information given to patients and caregivers should be customized to each point in the treatment journey and tailored to the patient's or the caregiver's own situations.

Realizing that healthcare providers (HCPs) play an important role in ensuring that patients and their caregivers receive information about their diagnosis, LUNGevity fielded the second phase of the study to understand the attitudes and practices of HCPs in disseminating materials for lung cancer. More specifically, we sought to:

- Measure the practice of dissemination of educational materials
- Uncover the barriers to dissemination of information

- Identify areas of satisfaction and dissatisfaction with materials related to various aspects of the lung cancer patient experience
- Identify preferred formats and information channels

APPROACH

LUNgevity, in collaboration with EdgeResearch, constructed a sequential mixed-method study to understand HCPs' attitudes about and usage of patient education materials. The first part of the study involved a quantitative analysis of the following HCP groups:

- 1) **Pulmonologists**, who often are the ones to diagnose a patient's lung cancer.^{11,12}
- 2) **Oncologists** from academic, community oncology clinics, and private practice setting, who treat lung cancer patients.
- 3) **Nurse navigators/Clinic or hospital administrators**, who manage patient education and also see lung cancer patients during their routine check-ups.¹³ Nurse navigators/community cancer center administrations often act as the gatekeeper of the clinic, handling and storing information.

These three groups were chosen in order to get a full and broad picture of education for lung cancer patients based on the specific role each group plays in a lung cancer patient's treatment journey. Each population provided important insights based on their role.

The recruitment and surveying were completed by EdgeResearch through an online platform. Response rates for the different HCPs were: oncologists (9%), pulmonologists (15%), and nurse navigators/clinic administrators (25%). Data from 216 HCPs (130 oncologists, 52 pulmonologists, and 34 nurse navigators and community cancer center administrators) were collected from September 21 through September 27, 2017. HCP profiles are available in the Appendix.

The quantitative phase was followed by a qualitative interview phase. An additional group of five HCPs, a mix of oncologists, nurse practitioners, pulmonologists, and social workers, was interviewed to explore and contextualize the survey findings on barriers to distribution, material needs, and gaps.

The study was IRB-approved by Schulman IRB (Protocol # 201706543).

MAJOR FINDINGS

Attitudes about treating an "an informed patient"

In the first part of the survey, we asked HCPs about their attitudes toward patient education and the role of patient education in healthcare decision-making. All HCPs surveyed express support for patient education and informed decision-making. Almost 90% of HCPs either

strongly or somewhat agree, for example, that the more informed their patients are, the better their decision-making about treatment for lung cancer. While about 75% do encourage patients to seek out additional information from non-profit and government organizations, there is some concern about patients going online to get information: 40% actively tell their patients not to go online because the information can be misleading or depressing.

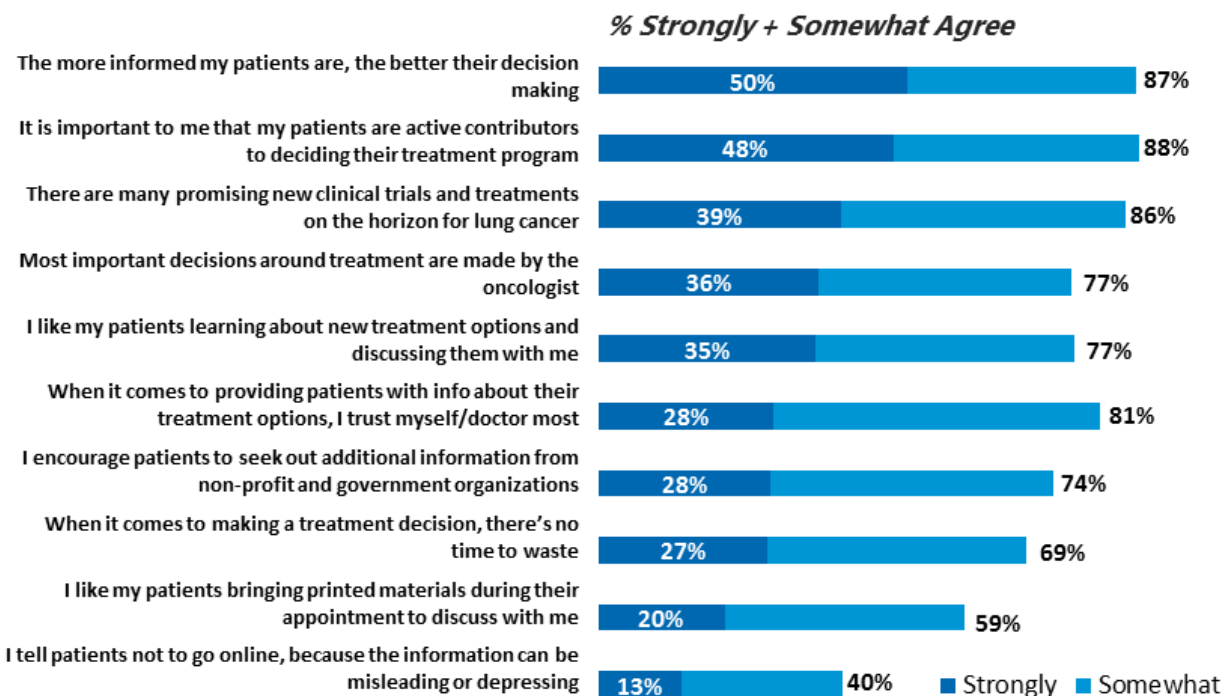


Figure 1, HCP Attitudes toward patient education (% of HCPs who strongly/somewhat agree)

Interestingly, when HCPs were asked about whether they trusted themselves when it comes to providing information to patients, only 28% of the respondents feel that they do so, suggesting that HCPs may often rely on other members of the healthcare team to provide information to patients or their caregivers.

While as a whole the HCPs support patient education and informed decision-making, oncologists (34%) are least emphatic about the importance of informed decision-making, as compared to pulmonologists (67%) and nurse navigators/community cancer center administrators (85%) (table 1).

	Oncologists	Pulmonologists	Nurse Nav/ CCC Admin
	<i>n=130</i>	<i>n=52</i>	<i>n=34</i>
The more informed my patients are, the better their decision making	34%	67%	85%
It is important to me that my patients are active contributors to deciding their treatment program	34%	67%	71%
There are many promising new clinical trials and treatments on the horizon for lung cancer	34%	50%	44%
Most important decisions around treatment are made by the oncologist	33%	37%	44%
I like my patients learning about new treatment options and discussing them with me	29%	50%	not asked
When it comes to providing patients with info about their treatment options, I trust myself/doctor most	25%	25%	44%
I encourage patients to seek out additional information from non-profit and government organizations	27%	23%	38%
When it comes to making a treatment decision, there's no time to waste	21%	38%	35%
I like my patients bringing printed materials during their appointment to discuss with me	19%	23%	not asked
I tell patients not to go online, because the information can be misleading or depressing	9%	8%	38%

Table 1, Differences in provider attitudes toward patient education (% of respondents who strongly agree)

This difference in attitudes between oncologists and the other HCPs may be attributed to that, as the treating physician, oncologists prefer their patients to have realistic expectations of what is possible as a result of treatment, a point that some patients indicated in evidence in the earlier, patient-facing study.¹⁰ In that study, one patient indicated that *“they feel their doctor is hesitant to be too hopeful, yet hesitant to be too truthful.”* This finding suggests the importance of the oncologist in transmitting education to their patients and caregivers, and establishes the oncologist as the *“trusted information source”* from a patient’s perspective. It also emphasizes the important of oncologists in the creation and dissemination of patient education materials.

Usage and Distribution of Patient Education Materials

We were also interested in learning about how HCPs use and distribute their current patient education materials. When asked about their practices for material distribution, over a quarter of the HCPs surveyed say they do not distribute patient education materials (figure 2).

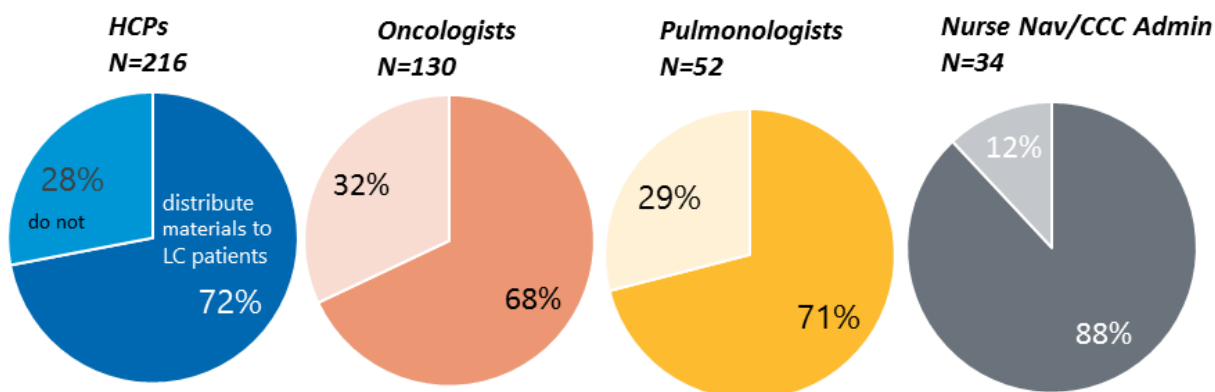


Figure 2, Percentage of HCPs who distribute lung cancer-specific materials or resource referrals to patients and caregivers. Smaller slices of the piecharts indicate proportion of HCPs who do NOT distribute materials.

Physicians (oncologists and pulmonologists) are less likely than nurse navigators and cancer care center administrators to distribute patient materials. There are several potential reasons for this, such as physicians perhaps not having as much time as nurse navigators to walk patients through materials. Physicians are also overall more unsatisfied with currently available education material, especially materials they might not see as accurate or helpful (table 1).

Practice Setting			Patient Volume			
Private Practice	Cancer Center	Hospital	1-20	21-49	50-99	100+
n=88	n=42	n=69	n=36	n=45	n=51	n=50
65% distribute	83% distribute	72% distribute	56% distribute	71% distribute	78% distribute	68% distribute

Table 2, Percentage of HCPs who distribute lung cancer-specific materials or resource referrals to patients and caregivers

When distribution behavior is analyzed by practice setting (table 2), comprehensive cancer centers correlate with greater distribution, indicating that when targeting specific settings for materials, more focus should be on private practice and hospitals to encourage more distribution. Furthermore, we found a strong correlation between patient volume and distribution of materials, indicating that low-volume practice settings do not distribute education materials.

HCPs were also asked more in-depth questions about their distribution practices to fully understand the process of distributing patient education to patients. These questions include how to maintain materials, who distributes the information, how to share information, and who receives the information.

Only a quarter of the HCPs interviewed have a point person on staff to review patient materials (figure 3). This point person is likely to be a nurse or physician, while other potential on-staff reviewers may be navigators, directors/managers, or educators.

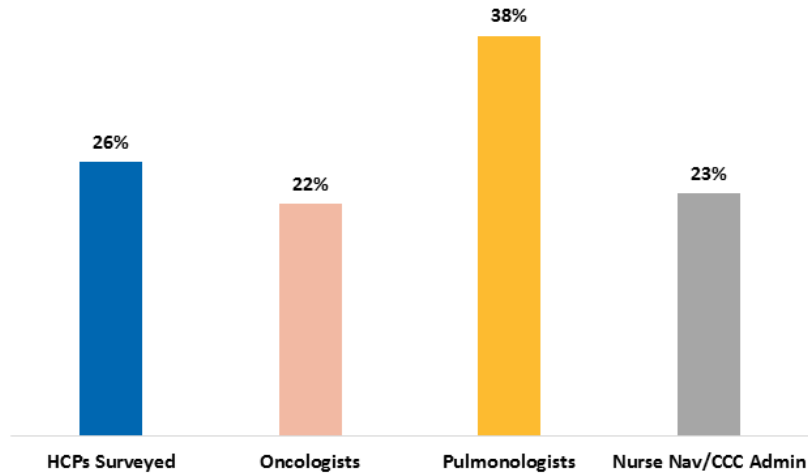


Figure 3, Percentage of HCPs with designated point person for materials review and maintenance

The HCPs were also asked about who specifically distributes materials. While 75% of the HCPs surveyed claimed that their organizations distribute materials, only about half say they distribute the materials themselves (figure 4).

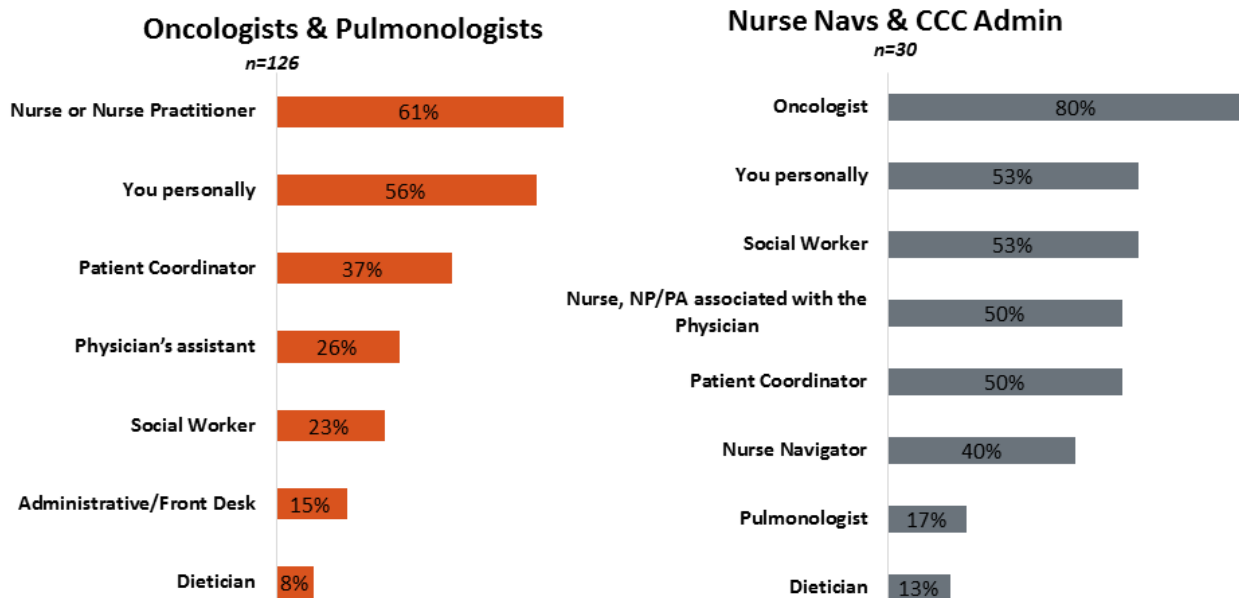


Figure 4, Distributors of patient education materials, according to HCPs

Interestingly, physicians claim that nurses most often distribute materials (61%), while nurse navigators and community cancer center administrators say oncologists most often distribute them (80%). This discrepancy may indicate a potential gap in material distribution: it is possible that some materials aren't being distributed because each group thinks the other is doing the distributing. This is concerning, as more patients may not be receiving information than suggested by the study respondents.

Notably, among the HCPs who reported that they distribute materials, when asked about whether they provide materials at different points of a patient’s journey or upfront at the time of diagnosis, only 44% report that they base their dissemination on a patient’s status. This finding is in stark contrast to the preference we found in our patient-facing study, where patients (or their caregivers) like to receive information at different points of their treatment journey (figure 5).

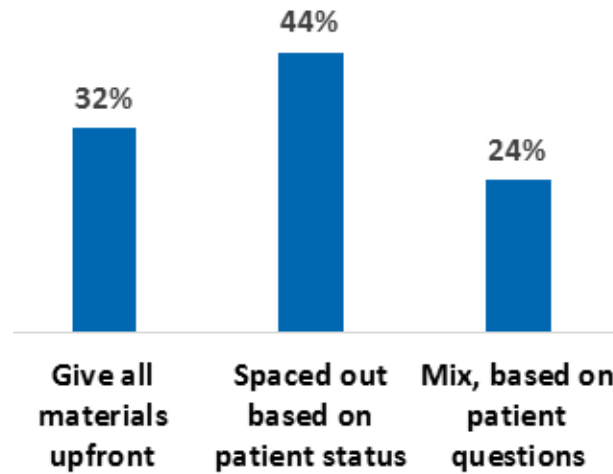


Figure 5, Distribution practice based on patient’s status

Cancer stage and histological subtype appear to influence the likelihood of HCPs disseminating education materials to their patients, with those in later stages (90%) receiving more education than those in earlier stages (71%). This trend seems most consistent amongst oncologists. Stage 1 NSCLC and SCLC patients are less likely than other lung cancer patients to receive materials. This may reveal a lack of materials available to them (figure 6).

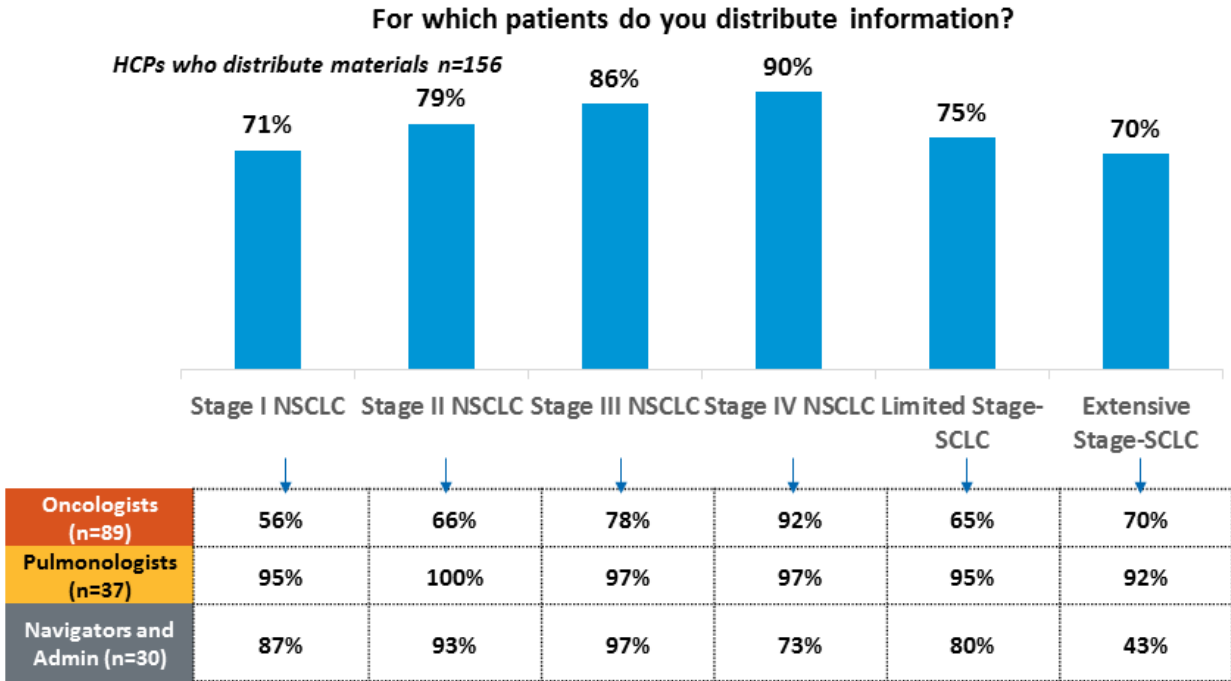


Figure 6, Distribution patterns of education materials based on type of lung cancer patients seen by different HCPs. Table below shows stratification of dissemination practices between different HCPs interviewed.

Current and preferred channels of disseminating patient education materials

HCPs were also asked in which formats patient education materials are shared in their organization (figure 7).

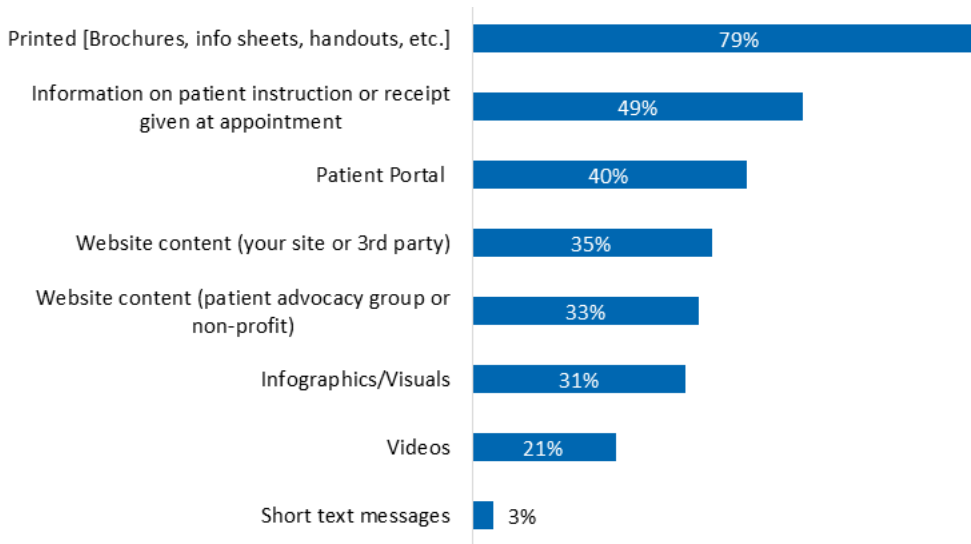


Figure 7, How patient education materials are currently shared

There is an inclination toward printed materials (79% of HCPs). However, qualitative feedback makes a case for electronic information. As one HCP states: *“lung cancer is a dynamic field and there is a danger [that] print information will be quickly outdated.”* There was a suggestion to combine the mediums, such as providing resources online that can be printed to ensure information is up-to-date, but also gives the HCP something tangible for the patient to walk away with.

While there was some differences between responses from oncologists and pulmonologists, the most significant differences were in nurse navigators and community cancer center administrators; they are more likely to be using alternative methods of getting information to patients, such as patient portals, websites, and visual aids such as infographics and videos (table 3).

	Oncologists	Pulmonologists	Nurse Nav/ CCC Admin
	<i>n=89</i>	<i>n=37</i>	<i>n=30</i>
Printed materials	76%	78%	87%
Info on patient instruction/receipt given at appt	38%	51%	77%
Patient portal	28%	46%	70%
Website content (yours or 3 rd party)	36%	27%	43%
Website content (patient advocacy/non-profit)	30%	30%	47%
Infographics/visuals	30%	27%	40%
Videos	13%	19%	47%
Text messages	3%	3%	3%

Table 2, Differences in material sharing, by provider type (% of HCPs who share each type)

When asked what their preferred channel of dissemination would be, more than half of HCPs indicate that printed materials are still the preferred format (figure 8).

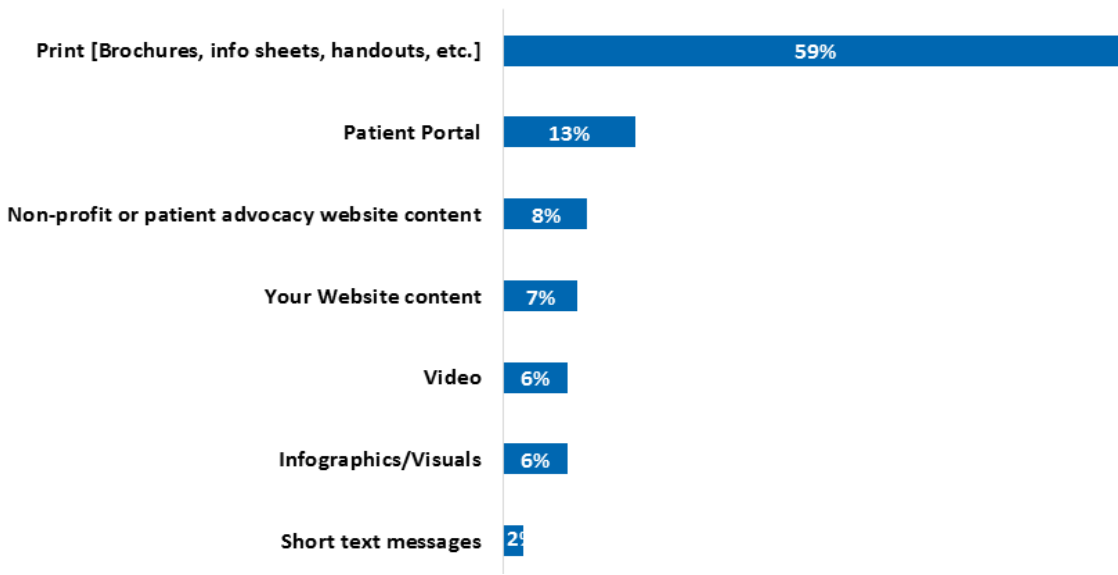


Figure 8, Preferred platforms for disseminating patient education material identified by HCPs

When probed further about their preferred patient education format, HCPs provide deeper insights. *“Written materials still work really well for people,”* one HCP reports. Another HCP suggests, however, that this material could do more than just be a printable document, stating, *“Need to have a better, whole packet that makes it interesting, relevant for patient to read all the information vs just hand out single pieces of paper.”* HCPs are looking for tangible materials, but still would like them to be up to date and polished, like hard copy materials.

However, some other HCPs are amenable to alternative ideas. One HCP proposes: *“Easy access to high quality material online, where I can just share a small card with all the material on it.”* While there is a clear preference for print materials, there is openness to new formats that might solve some of the other issues with patient education. This in-depth data suggests that HCPs ideally want a variety of materials available so that they can choose which works best for a patient.

Attitudes about currently available patient education materials

Respondents were then asked with the extent to which they like currently available patient education materials on various topics ranging along the lung cancer continuum, from diagnosis to treatment and supportive care. There are some topics that a bit over half of HCPs like, such as what to expect with chemotherapy (60% like these materials); explanation of disease (55% like these), and explanation and management of side effects (51% like these).

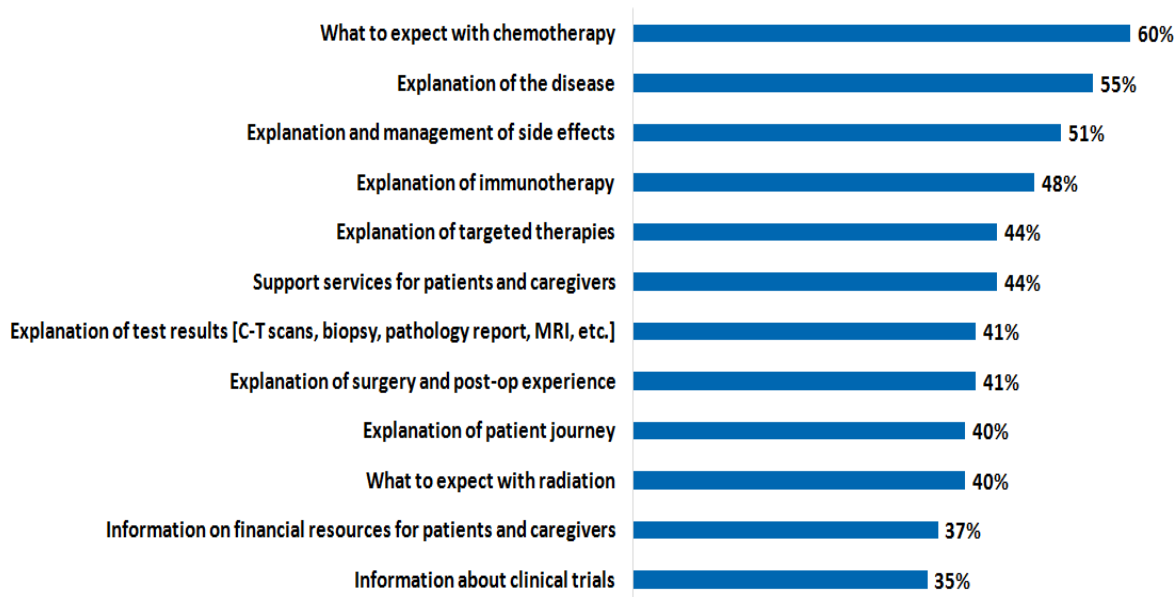


Figure 9, Percentage of HCPs who like each currently available patient material

However, fewer than half like the other patient education materials. These topics include information about clinical trials (35% like), information on financial resources (37% like), what to expect from radiation (40% like), and explanation of the patient journey (40% like). It appears that there is much room for improvement in the currently available materials (figure 9).

When probed further, HCPs provide insights into how exactly to make these resources more usable. For example, one HCP, discussing issues with financial resources, states, *“We have a charity system for patients who are un- or under-insured to help them gain access to care but it’s not really done in a comprehensive enough way.”* This suggests that patients have resources available that are underutilized due to lack of awareness; additional education could be the key to patients feeling more supported rather than creating additional programs that will once again be unnoticed.

About the patient journey, an HCP states, *“This is a challenge, each patient has a different journey. From prevention, screening, to end-of- life care.”* The HCP further clarifies that the patient journey includes end-of-life care. *“End-of-life care is something patients struggle with, need for better understanding of palliative care and idea of hospice care when it becomes necessary...doctors, not just patients, need help with this aspect.”* This suggests a gap in HCP education and a need to provide HCPs with resources and guides on how to talk to patients about difficult topics, such as palliative and hospice care, as part of the patient journey.

On information about clinical trials, one HCP reports, *“Value of clinical trials is a big one that needs more information, [such as] need for higher quality care and understanding how to*

identify it.” Education around the importance of clinical trials and how they are becoming the standard of care for certain subtypes of lung cancer is of paramount importance.

When data from the different HCP groups was analyzed separately, the results indicate that pulmonologists are overall less satisfied with current education materials than other HCPs (table 4). This is noteworthy, since a pulmonologist is often the diagnosing physician and should be engaged as a channel for disseminating patient education materials.

% Satisfied with Materials on this Topic	Oncologists	Pulmonologists	Nurse Nav/ CCC Admin
	<i>n=89</i>	<i>n=37</i>	<i>n=30</i>
What to expect with chemotherapy	61%	38%	83%
Explanation of the disease	55%	49%	63%
Explanation and management of side effects	52%	43%	60%
Explanation of immunotherapy	47%	32%	70%
Explanation of targeted therapies	46%	32%	50%
Support services for patients and caregivers	40%	30%	70%
Explanation of test results [C-T scans, biopsy, pathology report, MRI, etc.]	38%	41%	50%
Explanation of surgery and post-op experience	40%	30%	57%
Explanation of patient journey	39%	24%	60%
What to expect with radiation	39%	32%	50%
Information on financial resources for patients and caregivers	35%	24%	57%
Information about clinical trials	33%	30%	50%

Table 4, Percentage of HCPs by provider type who like each currently available patient material

Gaps in current patient education materials

When asked about gaps in currently available patient education materials (Figure 10), HCPs suggest that there is a lack of reliable and accurate patient materials on support services (47% of HCPs), financial resources (44%), and clinical trials (44%).

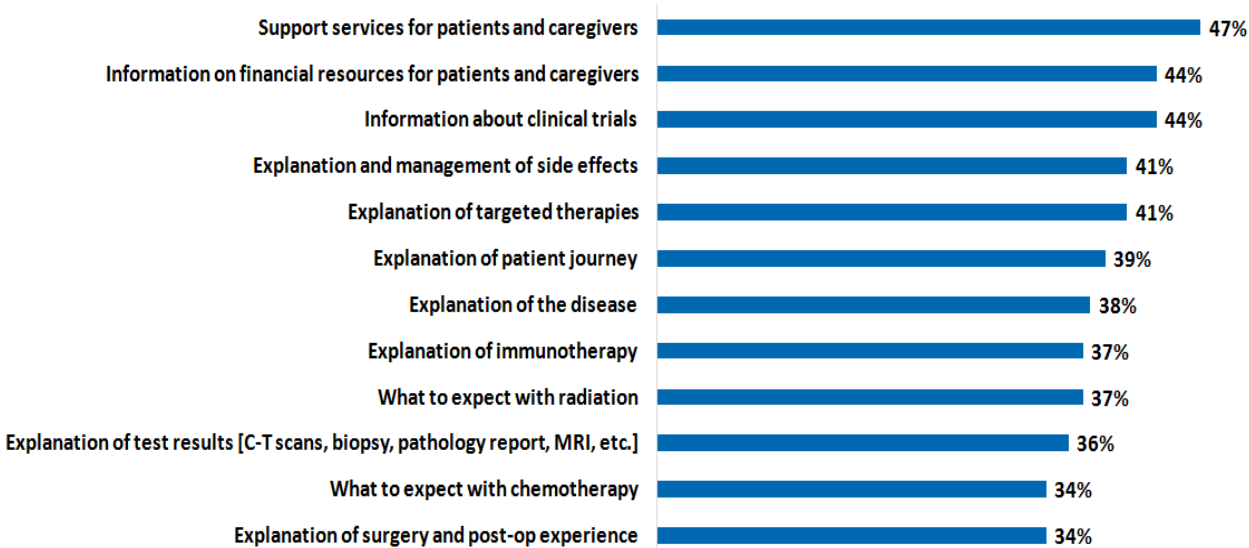


Figure 10, HCP-identified gaps in existing materials (% of HCPs who identify topic as a gap)

HCPs were asked for additional insights on these particular gaps, including solutions to these gaps.

On clinical trials, HCPs reported that there are websites that explain what clinical trials are and why they are important, but these websites have gaps when it comes to addressing logistical elements like “the pharmacy, the co-pay, and the support.” The logistical elements of clinical trial participation could be a barrier preventing patient participation; providing additional resources for these aspects of trials could result in a higher participation rate by patients.

As noted previously, HCPs reported that they have services and support for patients that patients are simply not well-enough informed on to take advantage of. Another gap identified, however, is outside support services education. The same HCP explains, “*We need more information about external resources than can be leveraged to help patients get access to lung cancer care.*” Another HCP states, “*[We need to be made known] what kinds of resources/support are available for patients and caregivers. We don’t have nearly enough in support infrastructure compared to what’s available for breast cancer survivors, for example.*” This indicates HCPs’ desire to provide patients the opportunity to take advantage of outside services; however, information needs to be available for this to be possible.

Additionally, HCPs report a need for more materials for explanation of test results. Many patients receive these results without context, which can make comprehending the results a challenge. Providing HCPs with a resource to go over the results with their patients might benefit patients’ comprehension.

More than a third of HCPs would like different materials for dealing with all aspects of treatment, indicating that HCPs may not distribute materials at all if they are not well satisfied with the materials they have.

Pulmonologists particularly feel these gaps (table 5), with more than half identifying a need for better information in what to expect with chemotherapy, an explanation of surgery and post-op experience, and support services for patients and caregivers.

% Would Like Better Materials on this Topic	Oncologists	Pulmonologists	Nurse Nav/ CCC Admin
	<i>n=89</i>	<i>n=37</i>	<i>n=30</i>
Support services for patients and caregivers	48%	59%	30%
Information on financial resources for patients and caregivers	44%	49%	37%
Information about clinical trials	46%	43%	37%
Explanation and management of side effects	39%	46%	40%
Explanation of targeted therapies	39%	41%	47%
Explanation of patient journey	38%	49%	30%
Explanation of the disease	34%	49%	37%
Explanation of immunotherapy	36%	51%	23%
What to expect with radiation	35%	38%	43%
Explanation of test results [C-T scans, biopsy, pathology report, MRI, etc.]	34%	38%	40%
What to expect with chemotherapy	33%	51%	17%
Explanation of surgery and post-op experience	29%	51%	27%

Table 5, Provider perception of information gaps in education materials

These gaps identified by pulmonologists are particularly important as pulmonologists treat the majority of surgery-eligible lung cancer patients. A pulmonologist reports, *“Surgery is not where the dynamic change in lung cancer care has happened, [but] more is needed around why quality of care is important for things like surgery and how important it is to have experience surgeons and to understand how proficient they are.”* This reiterates the need of a comprehensive education package that includes all treatment regimens.

Some other areas that HCPs feel have some gaps include explanations of therapies like immunotherapy and targeted therapies. One HCP states, *“There needs to be wider understanding of its [immunotherapy] application and limitations, helping patients understand and cope with side-effect profile or why it might not be the right treatment for them.”* This is important to note as HCPs like to provide patients with realistic information that does not provide false hope. This suggests a possible need for curated information inclusion in education materials as well as possible tonal changes. One HCP advised that patient advocacy organizations should *“be authentic, provide good, neutral information that grounds people.”*

This study demonstrates involving HCPs more in the educational materials process will be beneficial. HCPs are clear about what type of information they want to distribute, and therefore should be consulted in the development and creation of these materials. Thus, consulting HCPs early and often may result in more dissemination of materials if they find them more satisfactory.

Barriers to Distributing Patient Education Materials

Finally, HCPs were also asked about the barriers to distributing patient education materials (figure 11).

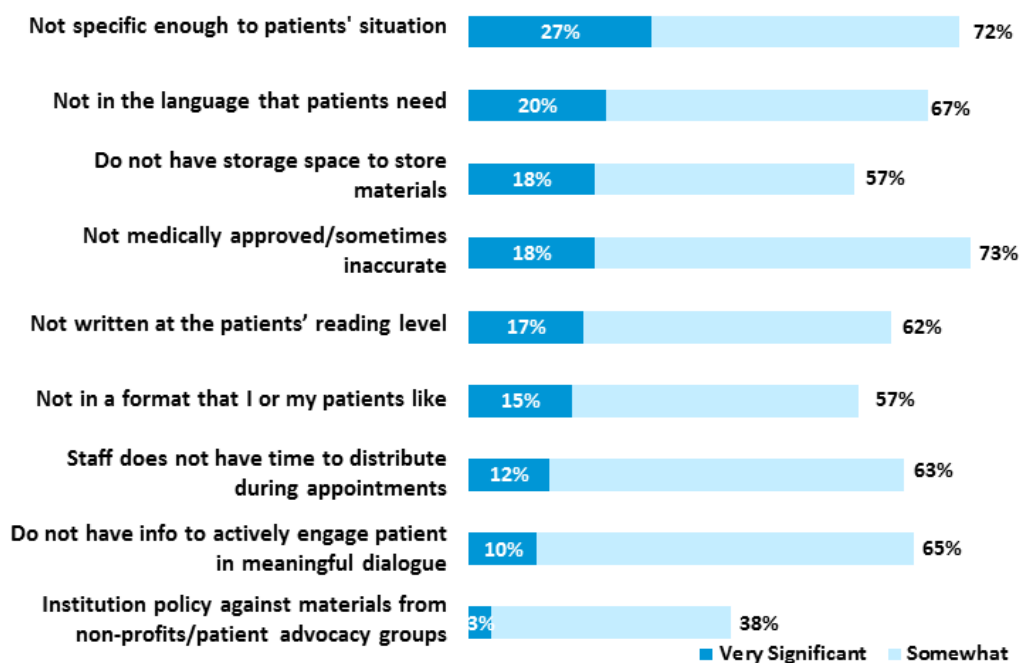


Figure 11, HCP-identified barriers to education materials distribution (% of HCPs who feel the barriers are very/somewhat significant)

Of the barriers presented, there is no single predominant hurdle; however, a number of barriers cause inaction. The top three barriers HCPs are concerned about are if the materials are medically approved/accurate (73% of HCPs identified it as a significant barrier); if the materials are specific enough to patients' situation (72%); and if the materials are in the language that the patients need (67%).

HCPs are looking for the right information at the right time to prevent patients “from having to wade through the whole book,” as one HCP from a cancer center says. Several of the HCPs suggest education for different points of the treatment journey, which would include general,

basic, broad information for a pulmonologist, but specifics on mutations and stages, etc. for an oncologist. One HCP seeks the ability to indicate to patients what the most relevant information to them would be. One HCP suggests a “*modular form with tear-away pages or sections of relevant information*” and another suggests “*a website that handles the branch points for decision making.*” HCPs want the ability to provide the information relevant to patients at that treatment point and the ability to provide new information as the patient progresses.

Another barrier HCPs identified is a lack of accuracy. There are concerns whether patients are receiving neutral, vetted, and up-to-date material: “*there are good resources and not good resources,*” as a social worker put it. The HCPs indicate they would like the ability to steer their patients to the right resources. In fact, when HCPs were asked if there would be interest in materials that could be branded with their own institutional logo (figure 12). Seventy-six percent of the HCPs are very-to-somewhat interested in the possibility of this type of material.

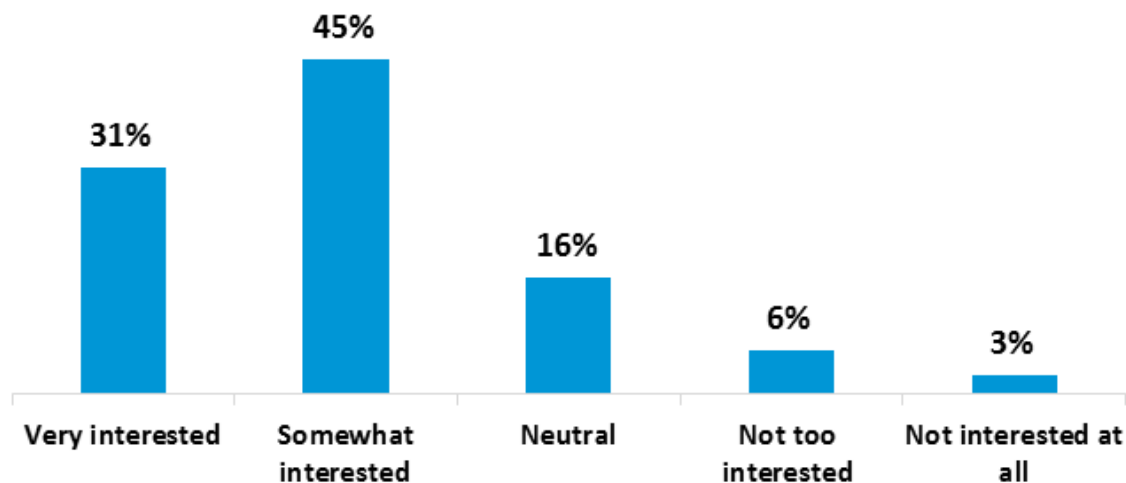


Figure 12, HCP interest in new patient education materials that can be customized, provided as printed, online, or through mobile app; and clinician-vetted and approved

HCPs also feel that language and understanding is a barrier in some patient education materials. In-depth interviews with HCPs indicate that having patient education materials available in layman’s terms is just as necessary as having materials in other languages. HCPs note that medicine is a very technical language, and many patients have limited comprehension; the ideal education would be easy to follow for both “a PhD and for no high school.”

English as a second language is also an issue for understanding patient education materials. HCPs report that, on average, 12% of lung cancer patients seen each year speak English as a second language. Furthermore, HCPs identify Spanish (96%), Mandarin (17%), Cantonese (7%),

other Asian languages (12%), and Arabic (12%) as those most often spoken by these patients. Some HCPs express a difficulty in communicating with non-English speaking patients and think that materials available in several languages might help with this. This would ensure that, even if a patient did not understand everything discussed in the office visit, they could revisit the information in hard copy in their own language in order to fully understand.

Finally, HCPs point out that some of their issues with patient education take place during the appointment. Many HCPs feel their own time constraints during the appointment. In addition to that, though, they also identify that patients’ willingness to talk or the ability to ask questions of their doctor can be a barrier. One HCP suggests that patients do not feel empowered enough to ask or to take up the oncologists’ time. As discussed in the early sections, this might be solved by providing both HCPs and patients with a guide to streamline the conversation. Providing both patients and HCPs with a question sheet might help HCPs prepare answers ahead of time and help patient ask the right questions when they are too overwhelmed with information to know what they don’t know.

One of the HCPs interviewed, a social worker, proposed another solution to the issue of HCPs’ time constraints. They discussed having a support group, moderated by the social worker, psychologist, and a thoracic oncologist, as a setting where patients are more open to talk and ask questions. This would alleviate both the pressure of an appointment and HCPs’ fears that patients have no other resources.

About half of HCPs combat some of these barriers by distributing materials from a combination of sources in order to ensure the best materials are distributed (figure 13).

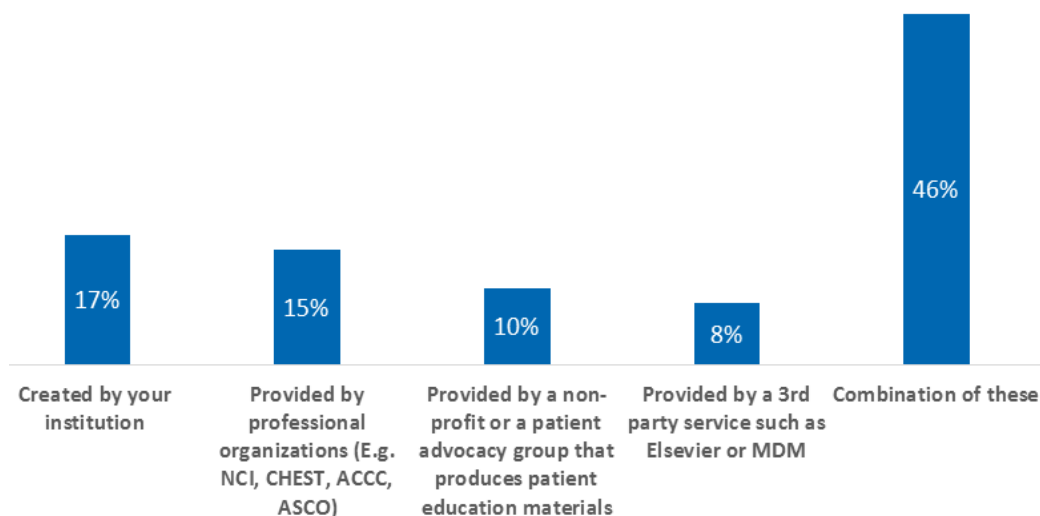


Figure 13, Sources of materials HCPs currently distribute (% of HCPs who distribute each)

When asked, HCPs state they are most likely (46%) to use a combination of materials created by their own institution, professional organization, patient advocacy group, or a 3rd party service such as Elsevier or MDM. This figure also suggests that if an organization receives materials, they will likely distribute them.

Based on the barriers HCPs discussed, there are many possible ways to ensure that more materials are being distributed. Providing specific and accurate information in several languages would relieve some of the burden on HCPs during the appointment time as they might feel less pressure to relay all the information a patient needs in one appointment. Support groups where patients can ask their questions are also a possible solution.

CONCLUSIONS/STUDY IMPLICATIONS

Our study demonstrated the importance of patient education in the eyes of HCPs. A summary of major findings and implications of these findings is provided in the following table:

Findings	Implications
While HCPs do want informed and engaged patients, this sentiment is not without reservation. Eighty-seven percent of HCPs surveyed report the importance of treating an informed patient. However, qualitative feedback underscored concerns measured in the survey over quality, accuracy, and realistic portrayals of treatment scenarios and options.	<i>It is not that physicians and others are discouraging patients from accessing information; but HCPs want to channel patients to information that is accurate, clear, and helpful.</i>
The most significant barriers to disseminating information are specificity to a patient’s diagnosis, accuracy, time, and clarity of scientific explanations. HCPs want patients to understand what is most likely going to be the outcome of their treatment, not necessarily every possibility available.	<i>Being able to customize information to patients’ situations would be welcome. An end-to-end source that can be accessed as needed would be welcome. Interestingly, patients and their caregivers also highlighted the importance of customized information – precise information about precision medicine!</i>
Practically speaking, dissemination practices vary widely, are often based on the HCP’s judgment and the patient’s status. This makes for inconsistent delivery of education materials.	<i>The main hurdle is how to get the right information to the patient at the right time and in a way that allows for discussion. Delivery prior to the appointment was suggested as a possible best practice.</i>
Further, there is typically no point person for materials curation and review; and most report cobbling together information from many sources. There is interest in a reviewed, vetted source.	<i>This suggests that even within a point of care, there may be no common sources or referrals going to all patients. It may also indicate more traction for a go-to source if one can be created.</i>
There is interest and desire for digital information	<i>It is easy for information to be out of date, making the</i>

sources, but HCPs still feel printed resources (59% prefer printed over other mediums) allow them to engage the patients more effectively and get information to a patient that allows them to understand it in their own time

case for web-based sources, but equally important to get something tangible in the hands of patients. Printable content would be valued. However, it is important to note that just handing over print materials is not sufficient and should not be considered shared decision making.¹⁴

Overall, our study also suggests that more HCPs should be consulted in the development and creation of patient education materials. The HCPs work with patients on a day-to-day basis and are aware of the sort of questions patients ask and the information they need to move forward in their treatment journey. Additionally, HCPs may benefit from resources geared toward them in order to better provide for patient, such as lists of additional external services or guides on how best to talk through tough topics like hospice care, palliative care, or test results; the only way to determine these needs would be to discuss with the HCPs. Thus, consulting HCPs early and often may result in more dissemination of materials if they find them more satisfactory. Collaboration with professional groups for the creation of these materials might result in more distribution.

LIMITATIONS OF THE STUDY

We note the following limitations of the study:

1. **Small Sample Size:** The sample size of this study (n=216) is small, particularly for nurse navigators/community cancer center administrators (n=34). A sample this size may not be fully representative of the HCP subpopulations present in this study.
2. **Weighting:** Our aggregate analysis of HCPs did not take into consideration the actual percentage of the overall HCP population that each subpopulation represents
3. **Population:** The participants of this study were both self-selected and self-reporting; self-selection and responder bias in the results is possible.
4. **Type of Study:** Though we have attempted to contextualize findings from the survey through in-depth interviews, we may not have captured additional insights that provide a deeper perspective to fully understand barriers and solutions to the problem.

Despite these limitations, the study highlights the importance of making changes to the current practices of creating and distributing patient education materials to lung cancer patients.

APPENDIX A

Characteristic of the survey respondents (N=216)

Practice Setting	Oncologists	Pulmonologists	Nurse Navigators/CCC Administrators
Private practice	52%	40%	9%
NCI Designated Cancer Center	12%	-	6%
Community Cancer Center	17%	12%	53%
Academic or Research Hospital	30%	31%	21%
Hospital (non-academic or non-research)	4%	23%	26%
Annual Patient Volume			
Less than 20	15%	31%	
21-49	24%	27%	
50-99	28%	27%	
100 or more	32%	15%	
Number of years in practice			
0-5 years	10%	13%	
6-10 years	27%	21%	
11-20 years	35%	33%	
20+ years	28%	33%	
Gender			
Male	75%	81%	15%
Female	22%	17%	85%
Prefer not to say	4%	2%	-
Age of HCP			
Less than 35	10%	4%	9%
35 to 44	32%	37%	38%
45 to 54	30%	29%	24%
55 to 64	20%	29%	29%
65 or older	8%	2%	-
Region			
Northeast	28%	23%	12%
Midwest	22%	37%	32%
South	28%	25%	26%
West	22%	15%	29%
Start of Patient Interaction			
Right at diagnosis	84%	94%	71%
Before they have begun a treatment	59%	50%	82%
After they have begun a treatment	40%	40%	71%

Other point in their treatment journey	4%	8%	9%
Primary Language of Patients Seen			
English Speaking	81%	84%	82%
English as a Second Language	13%	12%	12%
Do Not Speak English	6%	5%	6%
Language Spoken among those with English as a Second Language/Non English Speaking Patients			
Spanish	97%	91%	97%
Mandarin	10%	11%	45%
Cantonese	2%	13%	15%
Other East Asian language(s) like Vietnamese, Thai, Cambodian, etc.	8%	24%	9%
Arabic	10%	15%	12%
Other	6%	11%	3%
Language Accommodations (Interpreters/Staff Available for Translations)			
No, we do not have staff for interpreting	21%	30%	12%
Spanish	77%	61%	85%
Mandarin	19%	17%	33%
Cantonese	12%	17%	27%
Other East Asian language(s) like Vietnamese, Thai, Cambodian, etc.	14%	15%	24%
Arabic	14%	28%	21%
Other, please tell us:	3%	7%	9%

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