

Are lung cancer patients receiving education materials?

The healthcare-provider perspective on distribution gaps and possible solutions

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Background: While new treatments for lung cancer bring new hope, they can also make understanding a lung cancer diagnosis and making treatment decisions a challenge for both patients and caregivers. Education is imperative to understanding the diagnosis and making informed treatment decisions. However, many patients and their caregivers report that they do not receive materials from their doctors. We fielded a study of healthcare providers (HCP) to understand their attitudes and practices on disseminating patient education for lung cancer.

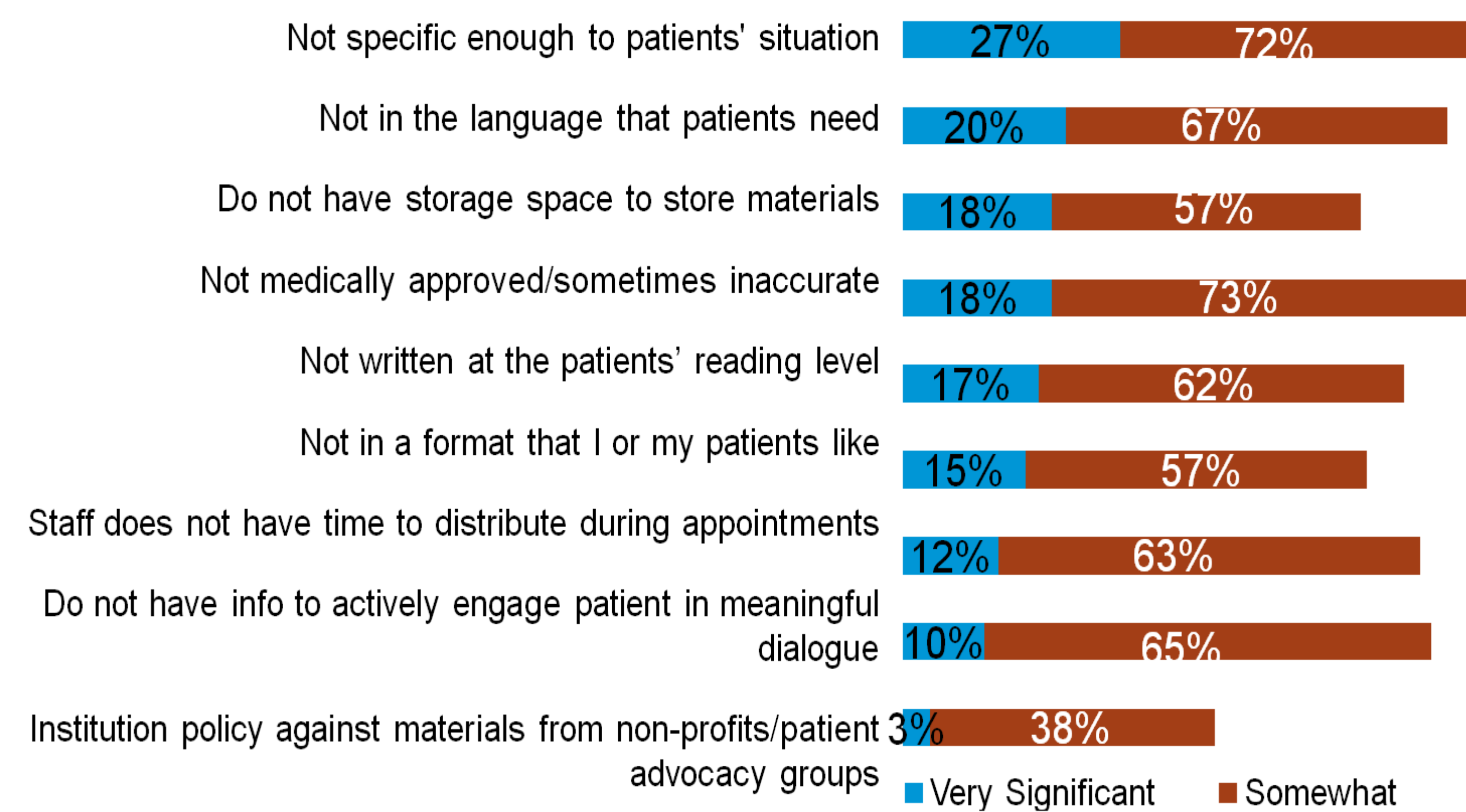
Methods: We conducted an IRB-approved sequential mixed-method study of 216 HCPs (130 oncologists, 52 pulmonologists, and 34 nurse navigators/cancer center clinic administrators [CCC]) from academic research centers, community cancer centers, and private practice to get a full and broad picture of education for lung cancer patients based on the specific role each HCP group plays in the treatment journey. The quantitative survey was followed by a qualitative interview of five HCPs to contextualize the survey findings. Questions of the study delved into perception, usage, distribution, and development of education materials.

HCP attitude toward patient education

% Strongly Agree	Oncologists n=130	Pulmonologists n=52	Nurse Nav/ CCC Admin n=34
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%

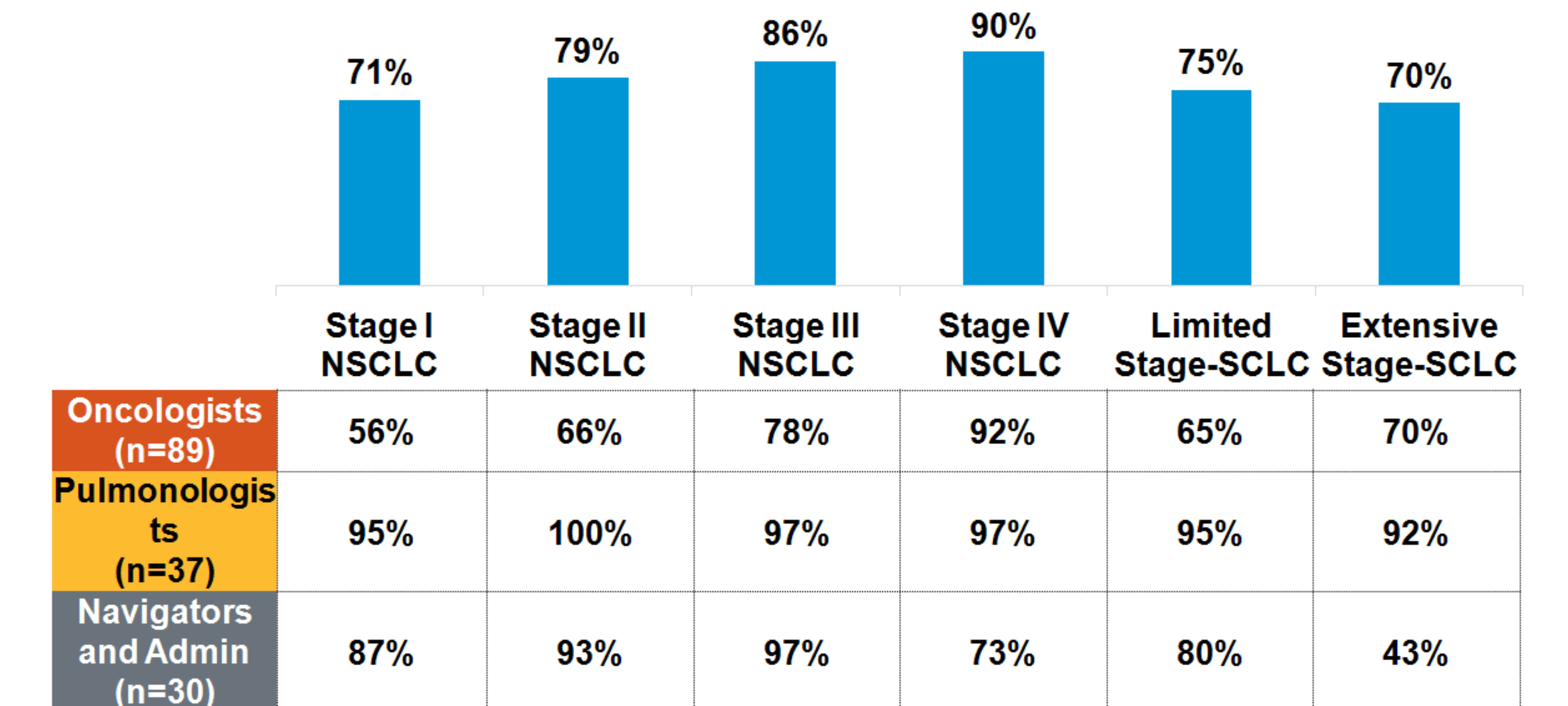
Oncologists appear to have more lukewarm attitudes toward patient education than do pulmonologists and those in patient support roles.

Barriers to distributing education materials



- No single barrier is the predominant hurdle, but many small barriers add up to inaction
- Specificity (customization to individual patient journey) and accurate, medically approved information appear to be the top barriers to address

Which patients receive materials?



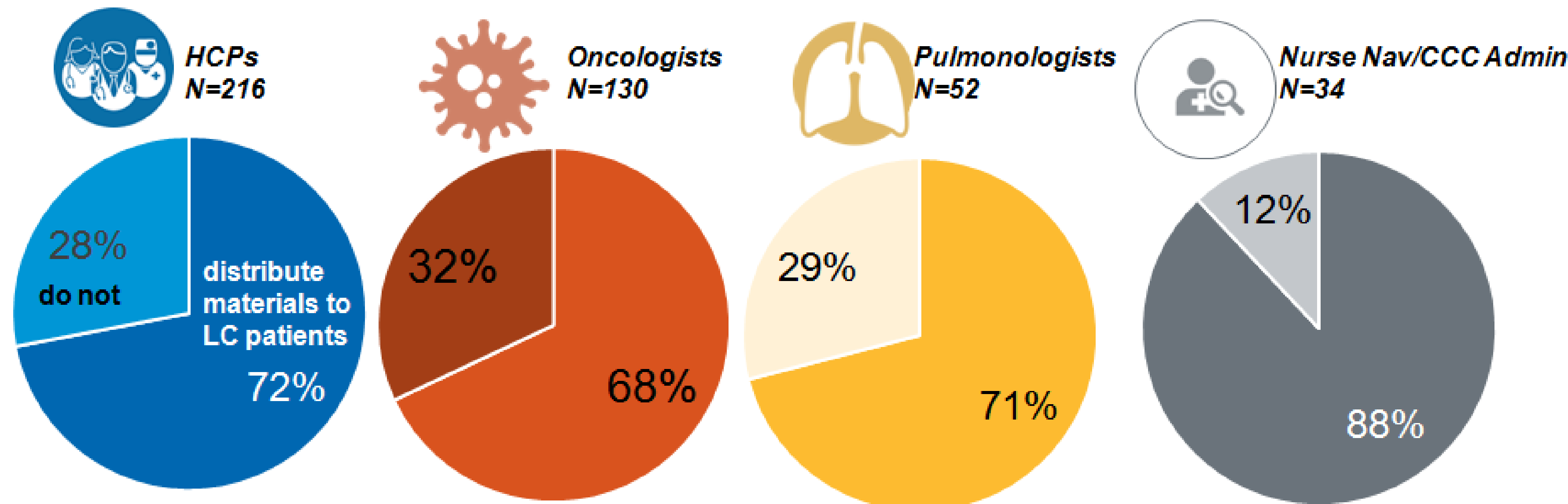
Cancer stage and type appear to influence the likelihood of HCPs getting education materials to the patient. This seems most true among oncologists.

Patient education material gaps identified

% Would Like Better Materials on this Topic	Oncologists n=89	Pulmonologists n=37	Nurse Nav/ CCC Admin n=30
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%

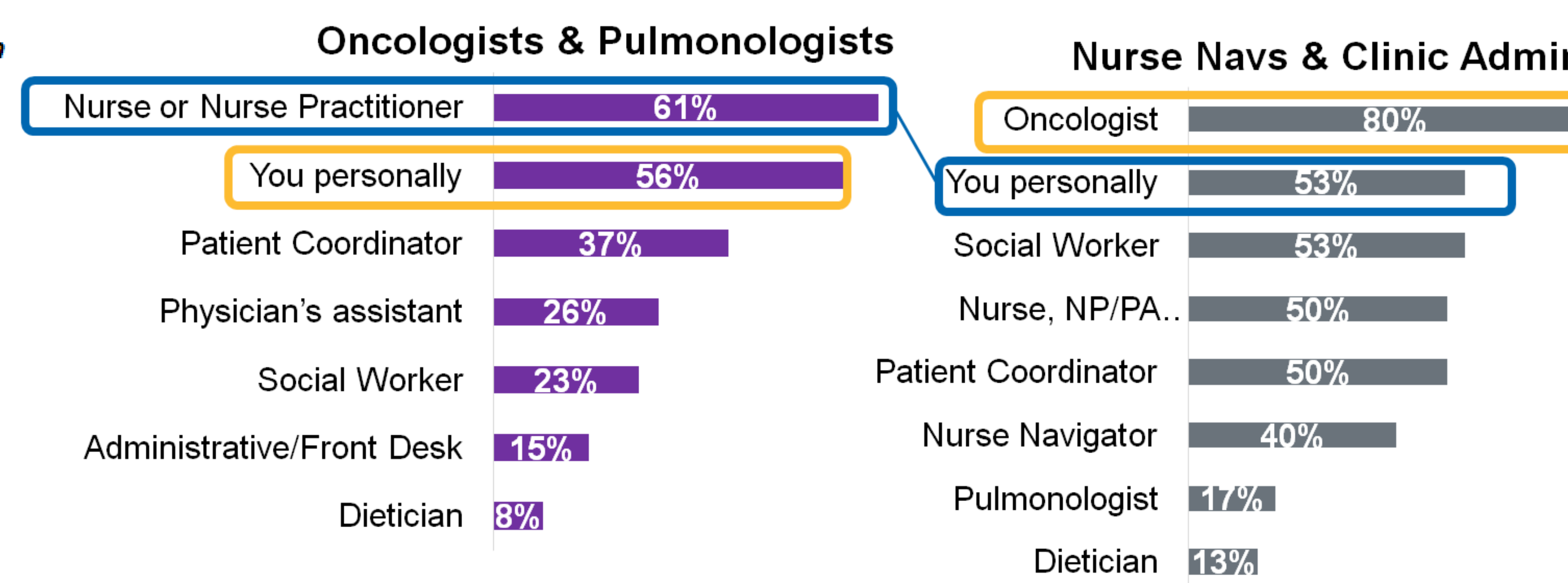
- HCPs are most lacking good information about support services, financial resources and clinical trials. More than a third would like different materials for dealing with all aspects of treatment.
- Pulmonologists are not likely to have good materials to help patient with the next step in treatment (surgery or chemo-radiation).

Do HCPs distribute patient education materials?



- Overall, over a quarter do not distribute LC patient education materials
- Directionally, physicians (oncologists and pulmonologists) are less likely to distribute materials than other HCPs
- The cancer center setting and higher volumes correlate with greater distribution

Who is actually distributing education materials?



- While nearly 3 in 4 say their organization distributes materials, only about half say they distribute materials themselves.
- Physicians say that nurses most often distribute materials, while nurse navigators and administrators say oncologists most often distribute them, leaving potential gaps in materials actually being distributed.

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.