Assessment of printed lung cancer surgery patient education materials in the United States

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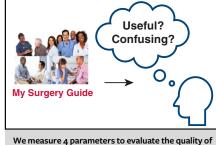
ABSTRACT

Objective: Well-designed patient education materials (PEMs) increase health literacy, which has been linked to better surgical patient outcomes. The quality of lung cancer surgery PEMs is unknown, however. Here we assessed printed lung cancer surgery PEMs for readability, understandability, actionability, and accessibility.

Methods: Various lung cancer programs throughout the United States were contacted for their lung cancer surgery PEMs. The readability of the received materials was calculated using 6 readability tests. Four thoracic surgeon–advanced practice practitioner dyads scored the PEMs for understandability, actionability, and accessibility using the Patient Education Material Assessment Tool and the Accessibility Assessment Tool, with the recommended minimum threshold of 70%. One-sample *t* tests were performed to compare each parameter against its recommended threshold.

Results: Out of 34 institutions contacted, 18 (52.9%) provided PEMs. The average reading level of the PEMs ranged from 7th grade to 11th grade, significantly exceeding the recommended 6th grade health literacy threshold (P < .01). Although mean understandability (73.7 ± 13.2%) and actionability (70.2 ± 17.8%) scores were not significantly different from the minimum threshold, and the mean accessibility score (81.8 ± 13.5%) was significantly higher than the threshold (P < .05), there was wide variation in the scores. Most PEMs scored well in organization and writing but lacked other features that can enhance patient understanding, such as visual aids and summaries.

Conclusions: PEMs are written at reading levels that are too advanced for patients. Although PEMs scored well in understandability, actionability, and accessibility, analysis of individual items revealed the need for improvement, including the use of shorter sentences, more visual aids and summaries, and expansion of language translations. (JTCVS Open 2024;22:530-9)



We measure 4 parameters to evaluate the quality of existing patient education materials for lung cancer surgery.

CENTRAL MESSAGE

Evaluation of a sample of lung cancer surgery patient education materials from across the United States shows that many are challenging for most patients to read and lack elements that can enhance understanding.

PERSPECTIVE

Well-designed patient education materials improve surgical outcomes. We evaluated the readability, understandability, actionability, and accessibility of patient education materials provided prior to lung cancer surgery from institutions across the United States and found that most existing materials need substantial improvements. We offer practical recommendations for enhancing patient education materials.

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Abbreviations and Acronyms			
AAT	= Accessibility Assessment Tool		
CLI	= Coleman-Liau Index		
FKGL	= Flesch-Kincaid Grade Level		
GFI	= Gunning Fog Index		
PEM	= patient education material		
PEMAT	T = Patient Education Materials Assessment		
	Tool		
SMOG	= Simple Measure of Gobbledygook Index		

Lung cancer resection is the gold standard treatment for early-stage lung cancer,¹ but perioperative outcomes may vary depending on the patient, hospital setting, operative volume, and surgeon expertise.² Additionally, effective patient education prior to surgery can improve perioperative outcomes. Preoperative education booklets decrease pain and anxiety while improving pulmonary function tests after lung surgery,³ and improving patient health literacy can reduce unnecessary hospitalizations^{4,5} and save \$25 billion per year.⁶ Nonetheless, there currently are no published assessments of the quality of patient education materials (PEMs) for lung cancer surgery.

The quality of PEMs directly impacts patient understanding and satisfaction. Higher quality materials lead to higher patient ratings for ease-of-use and increase the patient's ability to take better action from the information provided.^{7,8} Three parameters are commonly used to measure the quality of PEMs: readability (based on the length of words and sentences), understandability (qualitative review of organization and word choice), and actionability (qualitative review of how easily patients can follow action items).⁹⁻¹⁴

Many PEMs do not meet the threshold scores of readability, understandability, and actionability widely used to measure ease of patient use. For example, readability studies in thoracic surgery,^{15,16} orthopedics, and ophthalmology show that PEMs are consistently written at the 9th grade reading level,⁹⁻¹² higher than the 6th grade reading level recommended by the American Medical Association.¹⁷ Additionally, understandability and actionability studies in vascular and neurosurgery PEMs score a median of around 60%,^{13,14} with an accepted minimum threshold is 70%.⁷

In this study, we evaluated existing lung cancer surgery PEMs in the United States and provide recommendations for improvement (Figure 1). In addition to readability, understandability, and actionability, we also examined accessibility, given that >70% of patients undergoing lung cancer surgery are age >65 years,¹⁸ who show preferences for more accessible PEMs.¹⁹ Our findings provide insight into the quality of current PEMs and help offer recommendations on how they can be improved to better educate lung cancer surgery patients.

MATERIALS AND METHODS

Collection of PEMs

We emailed 34 surgeons from 34 different lung cancer programs across the United States (Figure E1), selected from CTSnet.org, and requested submission of all printed PEMs given to lung cancer surgery patients. Of the 29 surgeons (85.3%) who responded, 18 (62.1%) provided physical PEMs for this study, 7 (24.1%) did not have PEMs, and 4 (13.8%) reported that their PEMs were embedded in the institution's electronic health record. A total of 29 PEMs were compiled, with 5 institutions providing more than 1 type of document. Multiple documents per institution were included if they were all distributed preoperatively and differed in design, format, and/or publisher.

All identifying information was removed from each PEM before any evaluation was performed. The University of Chicago Institutional Review Board approved this study on December 19, 2022, and waived the requirement for informed consent (IRB22-1679).

Tests for Readability

Readability was measured by standard computational analyses.²⁰ Six different analyses were used to avoid assessment bias, including the Flesch Kincaid Grade Level (FKGL), Gunning Fog Index (GFI), Simple Measure of Gobbledygook Index (SMOG), Coleman-Liau Index (CLI), Fry Readability Graph (Fry), and Raygor readability graph (Raygor). PEMs were converted into plain text documents without formatting or pictures. The plain text document was then input into each readability analysis to yield a grade-level estimation level of education someone needs to easily read the text.

Grading Understandability, Actionability, and Accessibility

Understandability and actionability were graded using the Patient Education Material Assessment Tool (PEMAT),²¹ with a minimum accepted threshold of 70%.⁷ Accessibility, or how easily the material can be used by a diverse population of patients, was graded using the Accessibility Assessment Tool (AAT) developed under the guidance of the University of Chicago's Patient Education Department using feedback from surgeons, researchers, and patient education experts (Online Data Supplement, items 15-20). A final percentage score was calculated for each parameter using the tools. The minimum accessibility threshold for the AAT was set at 70% to align with the PEMAT model. Of the 39 total items in the PEMAT and AAT, 19 objective questions (eg, *Item C1: The material does not include advertisements*) were evaluated by the researchers to reduce survey fatigue in participants (Table E1).

Evaluation Dyads

Four clinician dyads were recruited from our institution's Thoracic Surgery Department. The dyads were composed of 1 thoracic surgeon and 1 advanced practitioner. The items on the PEMAT and AAT were condensed into a REDCap survey and distributed to the dyads. Each dyad member graded the same set of 7 to 8 PEMs. A Clinician Survey Guide (Online Data Supplement) was developed to explain each item on the survey and provide examples. Scores for each parameter were calculated and averaged within each dyad.

Statistical Analysis

Results were analyzed against recommended thresholds^{7,22} by 1-sample *t* tests. Each question item on the PEMAT and AAT questionnaires also was analyzed using descriptive statistics to determine how many PEMs met each criterion. The interrater reliability of each dyad was calculated using Cohen's κ and interpreted as follows: <0, no agreement, 0.01 to 0.20, none to slight agreement; 0.21 to 0.40, fair agreement; 0.41 to 0.60, moderate agreement; 0.61 to 0.80, substantial agreement; and 0.81 to 1.00, almost perfect agreement.

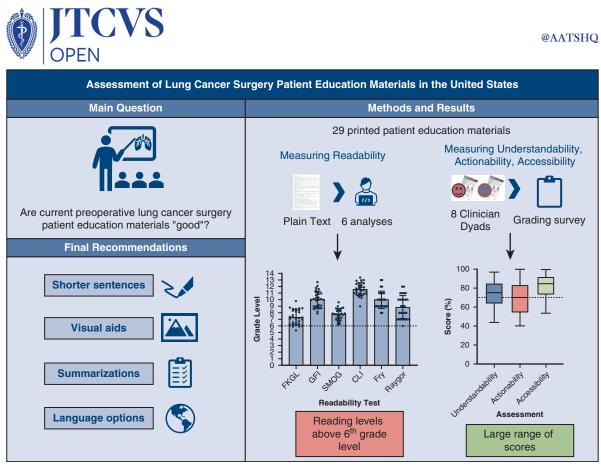


FIGURE 1. Graphical overview of the study.

RESULTS

General Characteristics of PEMs

Most of the programs that provided PEMs were academic (17/18). The programs had an average of 5.4 thoracic surgeons (range, 2-11), and 10 (55.6%) ranked in the top 40 institutions for pulmonary/lung surgery in the 2023 US News and World Report (Table 1). Most PEMs included both pre/ intraoperative and postoperative information (66%). All PEMs had been updated within the last 3 years (2020-2023), and they ranged from 1 page to 145 pages in length.

Readability

Using the 6 different readability analyses or indices, readability of the PEMs was significantly higher than the 6th grade level (P < .01). The highest average grade level measured was 11.60 (SD, 0.99) by the CLI and the lowest average grade level measured was 7.30 (SD, 1.13) by the FKGL (Figure 2, Table E2).

Understandability, Actionability, and Accessibility

The 4 dyads graded the understandability, actionability, and accessibility using the PEMAT and the AAT, with high interrater reliability scores ranging from $\kappa = 0.71$

(substantial agreement) to $\kappa = 0.82$ (almost perfect agreement). Average understandability (73.7%), actionability (70.2%), and accessibility (81.8%) all met or exceeded

TABLE 1. Characteristics of lung cancer surgery PEMs analyzed $\left(N=29\right)$

Characteristic	Category	Value, n (%)	
Institution type	Academic hospital	28 (97)	
	Private hospital	1 (3)	
Length	Short: <5 pages	10 (34)	
	Medium: 5-20 pages	11 (38)	
	Long: >20 pages	8 (28)	
Last updated $(N = 23)^*$	2020	5 (22)	
	2021-2022	8 (36)	
	2023	11 (48)	
Content type	Pre/intraoperative only	5 (17)	
	Postoperative only	5 (17)	
	Both pre/intraoperative and postoperative	19 (66)	

PEMs, Patient education materials. *Institutions for 6 PEMs did not provide last update dates; percentages are out of 23.

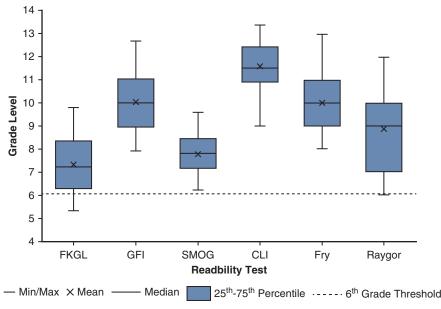


FIGURE 2. The average readability levels of patient educational materials calculated with 6 different readability analyses all exceeded the recommended maximum threshold of the 6th grade reading level. *FKGL*, Flesch-Kincaid Grade Level; *GFI*, Gunning Fog Index; *SMOG*, Simple Measure of Gobbledy-gook Index; *CLI*, Coleman-Liau Index; *Fry*, Fry Readability Graph; *Raygor*, Raygor Readability Graph.

the minimum threshold (Figure 3); however, the range of scores for each parameter was large, ranging from 40 to 100 (Table E3). A substantial proportion of PEMs had overall scores below the threshold (45% of PEMs in understandability, 48% in actionability, and 21% in accessibility). In addition, 17 out of 39 items (44%) on the PEMAT and AAT questionnaires were present in <75% of PEMs, and 6 out of 39 items (15%) were present in <50% of PEMs (Figure 4, Table 2).

In the understandability category, only 59% of PEMs satisfied item U2 ("The material does not distract from its purpose"). For example, 1 PEM detailed how a surgeon would operate the da Vinci robot: "Positioned alongside the bed, the patient cart holds the camera and instruments that the surgeon controls from the console." Only 66% of PEMs included a clear statement about the purpose of the PEM (item U1; eg, "Lung Surgery" is a vague title for preoperative material, while "What to expect after lung surgery" makes its purpose evident), only 74% used common everyday language (item U3; eg, "redness and/or swelling" is everyday language, rather than "inflammation"), and only 71% presented information in a logical sequence (item U10; eg, chronologically, most important information first). Summarization and visual aids also were lacking in most PEMs, and 36% of PEMs actually had visual aids that were distracting (eg, photos of health care providers on a page with information about thoracoscopies and thoracotomies) (Table 2).

In the actionability category, only 44% of materials satisfied item A4 ("The material provides a tangible tool whenever it can help the user take action"). Examples of tangible tools from some PEMs included checklists. Some PEMs included space for patients to write down their answers to questions such as "Who will drive me to and from treatment?" to help them organize their tasks before surgery. Only 31% of materials satisfied A7 ("The material uses visual aids whenever it

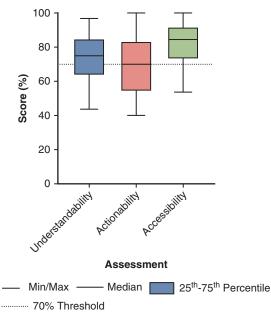


FIGURE 3. The average understandability, actionability, and accessibility scores of lung cancer patient education materials met or exceeded the minimum threshold score of 70% but showed a wide range of scores.

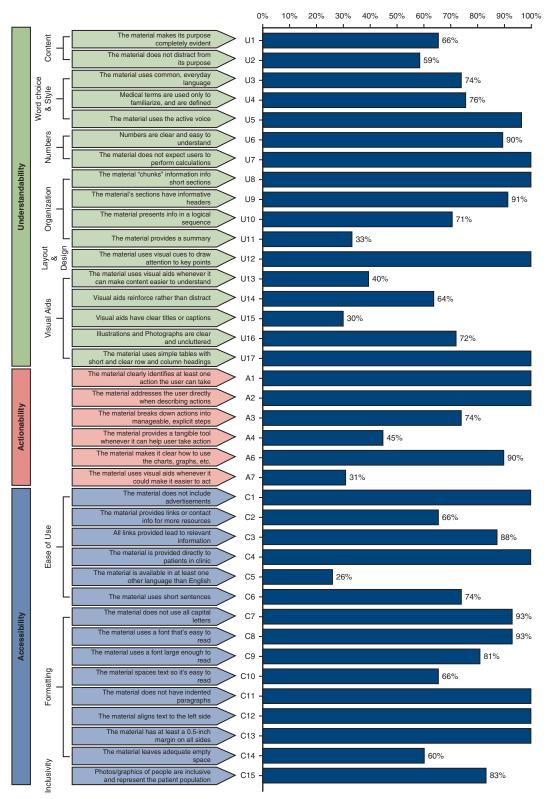


FIGURE 4. The percentage of patient education materials that satisfied each item on the assessment tools.

could make it easier to act"). For example, 1 PEM provided written instructions on how the patient needed to use the incentive spirometer (eg, "*This device is very important to*

use after your surgery in order to help prevent complications such as pneumonia. To do these exercises, you will breathe in slowly with your mouth and not your nose") but did not

Item	Statement	%	Recommendations
U1	The material makes its purpose completely evident	34	Use specific titles for sections of information.
U2	The material does not distract from its purpose	41	Do not include information or visuals that may confuse or overwhelm patients.
U3	The material uses common, everyday language	26	Keep the vocabulary at 6th grade reading level.
U10	The material presents info in a logical sequence	29	Maintain a chronological order of information when possible.
U11	The material provides a summary	67	Include a numbered or bullet point summary of the most important points.
U13	The material uses visual aids whenever it can make content easier to understand	60	Use relevant graphics, pictures, or drawings to illustrate any information that can be seen visually, such as the placement of c
U14	Visual aids reinforce rather than distract	36	hest tubes or instructions for skin preparation. Include a caption for
U15	Visual aids have clear titles or captions	70	every visual aid to ensure that the patient can clearly understand it.
A3	The material breaks down actions into manageable, explicit steps	26	Every instruction should be step-by-step and easy to execute.
A4	The material provides a tangible tool whenever it can help the user take action	55	Materials should provide checklists or forms for patients if there is an action they are requested to take. Actions should be illustrated
A7	The material uses visual aids whenever it could make it easier to act	69	when possible, to decrease confusion.
C2	The material provides links or contact info for more resources	34	Provide direct links to additional resources or contact information.
C5	The material is available in at least one other language than English	74	Materials should be available in different languages. If not, translations of content should be provided if requested.
C6	The material uses short sentences	26	Sentences should be around 10 words or less.
C10 C14	The material spaces text so it is easy to read The material leaves adequate empty space	34 26	Use at least the same size font space between paragraphs, add 1.5 spacing between bullet points and lists, and use 1.15 spacing between sentences. Aim for 10-35% of empty space per page.

TABLE 2. Recommendations for future PEMs based on poorly met items (<75%) in the study

PEMs, Patient education materials. *Percentage of PEMs that did not meet the statement.

provide a visual aid to show the correct sitting position and the correct way to hold the spirometer or indicate the different parts of the spirometer. Only 74% of PEMs provided explicit steps (item A3). For example, one PEM states "*You may start a heart-healthy, low-sodium diet*" but does not provide any additional information about the contents of a heart-healthy diet or low-sodium diet. PEMs meeting the item A3 requirement provided details about the serving sizes of meat, dairy, and vegetables.

In the accessibility category, only 26% of materials met item C5 ("The material is available in at least one other language than English"). In addition, only 60% of materials left adequate empty space for ease of reading (item C14), and only 66% of materials left enough space between lines of text (item C10). Based on our findings, we make several recommendations for PEMs in Table 2.

DISCUSSION

High-quality PEMs increase patient health literacy and improve surgical outcomes. With no currently published research on the quality of lung cancer surgery PEMs, this study sought to provide a quantitative and qualitative review of the state of PEMs in the US, as well as recommendations for improvement.

Implications

Our findings show that readability, understandability, actionability, and accessibility of lung cancer surgery PEMs often do not meet the standards for optimal patient health literacy. To reduce readability assessment bias, we applied 6 different readability scales/tests/indices (Figure 2).²⁰ While the CLI requires a large corpus of text, the Fry and Raygor graphs take small samples from throughout the text; yet all of the PEMs were written at a higher grade level than the American Medical Association recommendation of a 6th grade reading level,²² consistent with surgery PEMs in other specialties.^{9-12,23} Readability can be improved by using shorter sentences and shorter words. Improving the readability levels of PEMs could have a tangible impact on surgical outcomes.²⁴ Similar studies of online PEMs on lung cancer screening^{25,26} and thoracic surgery¹⁵ that focused on readability consistently showed that materials are written above the recommended 6th grade level; however, our study is the first to comprehensively evaluate the holistic quality of lung cancer surgery PEMs given to patients clinics and to provide recommendations in for improvement.

Readability assesses the length of words and of sentences, but it does not assess reader appeal. Understandability assesses the presentation and considers the meaning of the words, and actionability assesses how easily patients can follow and execute tasks described in PEMs. PEMs with higher understandability and actionability scores are usually rated by patients as easier to understand.⁷ In the present study, both understandability and actionability scores varied widely, with many PEMs scoring below the threshold, consistent with PEMS in surgery^{13,14} and oncology.²⁷ As with readability, this is the first study to apply the PEMAT method to lung cancer surgery PEMs specifically.

Potential strategies to improve the understandability and actionability of lung cancer surgery PEMs include the provision of tangible tools and visual aids for recommended actions and tasks. A Canadian study of 786 provincial cancer agencies' online PEMs showed deficits in understandability and actionability scores (ranging from 57% to 86%) and made similar recommendations for improvement, including incorporating visual diagrams, everyday language, clear document aims, and key takeaways and summaries.²⁷ Using visual aids to aid understandability and actionability is a common recommendation to improve PEMs, especially for patients with low health literacy, such as English as a Second Language speakers, patients with disabilities, and older adults (>65 years).^{8,14,19,22,28} Patients prefer visual PEMs over words-only PEMs and can take more effective actions with visual PEMs (eg, bowel prep before colorectal surgery).^{8,28} Other ways to improve understandability are to use plain language that is concise, specific, and relevant and to provide clear organization and concise summaries.

Our present study is innovative in including the creation of an accessibility parameter for evaluation, recognizing the predominance of older adults among lung cancer surgery patients.¹⁸ A scoping review of PEM preferences of older adults identified larger text size, signposted information, and inclusive images relevant to their age as key desired accessibility features.¹⁹ We found that the PEMs were generally accessible for older adults, except with respect to language translation availability and providing sufficient white space for reading ease. Future studies should incorporate accessibility measurements to offer a more comprehensive overview of PEM quality.

Interestingly, all programs that submitted PEMs indicated that their materials had been developed and approved by a Patient Education Department. The wide range of scores suggests that standards for Patient Education Departments may vary across the United States. Standardization of thresholds and scores for PEMs has been achieved in other countries. For example, in one regional health service in Australia, a globally coordinated health literacy approach succeeded in raising average PEMAT scores by 5% in understandability and by 4% in actionability.²⁹ Instituting national minimum guidelines or a standardized review process could help improve the quality of PEMs.

Limitations and Future Recommendations

This study has several limitations. The study collected PEMs from a sample of mainly academic institutions, which could introduce sample bias. It is possible that academic institutions are more likely to have lung cancer surgery programs and to have created lung cancer surgery PEMs. However, there was variation in the size of departments and rankings of departments in the US News and World Report, indicating diversity of the programs submitting the PEMs for this evaluation. We also were limited in the number of materials that we could evaluate, as each PEM underwent comprehensive grading using 2 evaluation tools, and the availability of graders (8 practicing clinicians) was a limited resource. We limited the scope of this study to PEMs existing in print format only. This scope was chosen to focus specifically on institutional materials provided to all patients by their hospital, rather than to evaluate a plethora of varied materials that could be accessed independently by each patient. Also of note, 87% of the institutions that we contacted still used paper format PEMs to hand out to patients; however, with more patients accessing online information and the integration of PEMs into electronic health record systems (eg, MyChart), the quality of such online PEMs should be assessed in future studies.

The PEMAT scoring system has been vetted to be consistent across both hospital staff and patients,³⁰ but the AAT is a new tool. Our evaluating dyads were composed of clinical providers only, and the addition of a nonclinical evaluator in future studies may decrease bias and confirm the reliability of the AAT. Finally, while our study was novel in including holistic analyses that considered older patients' preferences for PEMs, it did not include evaluations in the context of elderly and/or sight-challenged individuals.

CONCLUSIONS

Most lung cancer surgery PEMs are accessible and appear to be designed with an older population in mind. However, all are written at reading levels deemed too high for patients. Many patients have deficits in understandability and actionability, which limit comprehension. We recommend that PEMs use shorter sentences, more visual aids, summaries, and multiple languages. Although this study focused specifically on the quality of presentation, future research needs to investigate the quality of content of lung cancer surgery PEMs and how surgeons may use PEMs to guide conversations with their patients.

Conflict of Interest Statement

Dr Donington reports receiving speaking honoraria from and advising for Amgen, AstraZeneca, BMS Merck, and Roche/Genentech. All other authors reported no conflicts of interest.

The *Journal* policy requires editors and reviewers to disclose conflicts of interest and to decline handling or

reviewing manuscripts for which they may have a conflict of interest. The editors and reviewers of this article have no conflicts of interest.

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Key Words: patient education materials, readability, understandability, accessibility, lung cancer surgery

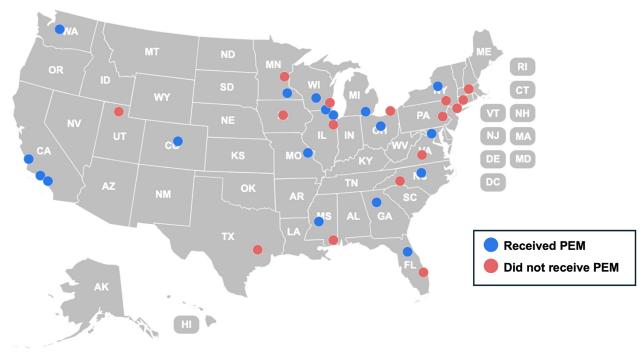


FIGURE E1. Geographic distribution of institutions invited to participate in the study.

TABLE E1.	Objective items from	the PEMAT and A.	AT that were reviewed	l separately by researchers
	Objective nemis nom	the i mining and and	II that were reviewed	separately by researchers

Item	Statement
U5	The material uses active voice.
U7	The material doesn't expect the user to perform calculations.
U8	The material breaks or "chunks" information into short sections.
U11	The material provides a summary.
U12	The material uses visual cues (eg, arrows, boxes, bullets, bold, larger font, highlighting) to draw attention to key points.
U15	The material's visual aids have clear titles and captions.
U17	The material uses tables with clear headings.
A1	The material clearly identifies at least 1 action the user can take.
A2	The material addresses the user directly when describing actions.
A4	The material provides a tangible tool (eg, menu planners, checklists) whenever it could help the user take action.
C1	The material does not include advertisements.
C2	The material provides links or contact information for more information.
C3	All links provided lead to a relevant page.
C4	The material is directly provided to patients.
C5	The material is available in at least 1 other language.
C7	The material does not use all capital letters.
C11	The material does not have indented paragraphs.
C12	The material aligns text to the left side.
C13	The material has at least 0.5-inch margins.

PEMAT, Patient Education Materials Assessment Tool; AAT, Accessibility Assessment Tool.

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PEM no.	Readability test scores (grade level)*						
	FKGL	GFI	SMOG	CLI	Fry	Raygor	
1	5.9*	9.1	6.9*	11.4	9	8	
2	7.2	9.9	7.9	10.9	9	7	
3	8.2	11.2	8.3	11.7	10	8	
4	8.8	11	8.6	12.7	13	11	
5	6*	8.2	6.3*	11.4	8	7	
6	7	10.1	7.7	10.8	9	7	
7	7.3	10	7.8	11.9	9	7	
8	6.2	8.9	7.1	11.9	10	10	
9	7.1	10	7.9	10.4	9	7	
10	5.3*	7.9	6.2*	9	8	6	
11	7.6	10.3	7.7	12.9	12	12	
12	8.7	11.8	8.7	12.5	13	11	
13	8.4	12.1	9	10.9	10	9	
14	9.8	12.7	9.6	13.4	12	11	
15	6.7*	9	7.2	11.2	9	9	
16	8.1	10.9	8.3	12.2	11	10	
17	7.1	10.3	7.8	10.9	9	9	
18	8.6	11.1	8.3	13	11	12	
19	6.3*	8.6	6.6*	11	10	10	
20	6.1*	8.6	6.5*	11.8	10	10	
21	8.6	11.6	8.8	13	11	8	
22	7.4	10.1	7.9	11.5	9	8	
23	5.9*	8.7	6.8*	11.1	9	7	
24	6.2*	9	7.2	10.3	10	7	
25	6.5*	8.7	7.3	10.9	9	7	
26	6.5*	9.2	7.5	10.6	9	8	
27	8.7	10.7	8.7	12.1	10	11	
28	8.3	11.5	8.6	12.5	11	10	
29	7.3	10	7.8	12.4	11	10	
Average	7.30	10.04	7.76	11.60	10.00	8.86	
SD	1.13	1.26	0.86	0.99	1.34	1.75	

TABLE E2. Individual and average scores of readability analyses conducted on PEMs for lung cancer surgery

PEM, Patient education materials; FKGL, Flesch-Kincaid Grade Level; GFI, Gunning Fog Index; SMOG, Simple Measure of Gobbledygook Index; CLI, Coleman-Liau Index; Fry, Fry Readability Graph; Raygor, Raygor Readability Graph; SD, standard deviation. *Scores at or below the recommended reading threshold of 6th grade level for patient education materials.

TABLE E3. Understandability, actionability, and accessibility score distributions

Parameter	% met*	Mean (%)	SD	Range, %
Understandability	55.17	73.68	13.17	43.75-96.88
Actionability	51.72	70.23	17.79	40.00-100
Accessibility	79.31	81.82†	13.47	53.57-100

*Proportion of materials that met or exceeded the 70% threshold. \dagger Significantly higher than 70% threshold (P < .05).