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# Helping Patients Understand Pancreatic Cancer Using Animated Pancreas Patient Education With Visual Formats of Learning

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**Objectives:** Patient education and resources that address barriers to health literacy to improve understanding in pancreatic cancer are limited. We evaluated the impact and outcomes benefits of Animated Pancreas Patient (APP) cancer educational modules (APP website and YouTube).

**Methods:** A retrospective study of APP metrics and utilization data from September 2013 to February 2021 was conducted. We evaluated audience reach and calculated top views by media type (animation/expert video/patient video/slideshow) and top retention videos from the modules.

**Results:** During the study period, APP had 4,551,079 views worldwide of which 2,757,064 unique visitors or 60% were from the United States. Of these, 54% were patients, 17% were family members or caregivers, 16% were health care providers, and 13% were other. The most popular topic viewed among the animations was “Understanding Clinical Trials” (n = 182,217), and the most common expert video viewed was “What are the different stages of pancreatic cancer?” (n = 15,357).

**Conclusions:** Pancreatic cancer patient education using APP's visual formats of learning demonstrated a wide reach and had a significant impact on improved understanding among patients, families, and caregivers. Continued efforts should be made to provide patient resources that address health literacy, better quality of life and improved health outcomes in pancreatic cancer.

**Key Words:** health literacy, health outcomes, pancreatic cancer, patient education, visual formats of learning

(*Pancreas* 2022;51: 628–633)

Pancreatic cancer (PC) is a leading cause of cancer mortality in the United States, with an estimated 60,430 new diagnoses and 48,220 deaths in 2021.<sup>1</sup> Pancreatic cancer is also a leading cause of mortality among cancers of the digestive system.<sup>2</sup> The relative 5-year survival of all types of PC was 10.8% between 2011 and 2017; PC is estimated to account for 7.9% of all cancer-related deaths in 2021.<sup>3</sup> Because the survival rates for PC patients are dismal, understanding mechanisms of early events in disease development and new approaches for early detection and management is necessary for better outcomes.<sup>4</sup>

One of the key factors that can negatively impact patients' health outcomes is low health literacy.<sup>5–9</sup> Prior studies have linked lower levels of health literacy to poorer health-related quality of life<sup>10</sup> and a lower likelihood of receiving chemotherapy (cancer patients).<sup>11</sup> Although there are several reports on increasing burden of pancreatic diseases, data on patient education on quality of life and health outcomes for PC are limited.

In this study, we evaluated the impact of National Pancreas Foundation's (NPF's) Animated Pancreas Patient (APP) PC educational modules using visual formats of learning to improve patient understanding for over a period of 7 years.<sup>12,13</sup> We assessed APP's role in addressing patient gaps in understanding by reducing learning barriers for patients to make informed decisions, improve behaviors, and partner with their health care providers to attain optimal health outcomes.

## MATERIALS AND METHODS

### Study Design and Participants

This is a retrospective study of APP website and YouTube audience metrics for learner activities related to PC education, from September 2013 to February 2021. The APP website was launched by the NPF in September 2013; we therefore included all PC metrics from September 2013 to February 2021, the latest measurable month. Participants visiting the APP's PC modules on the website and YouTube channel were comprised of patients and their family/caregivers and health care professionals.

### Content Development and Access

The educational content for the APP PC resources was developed by NPF's multidisciplinary scientific advisors consisting of gastroenterologists, endoscopists, pancreatic surgeons, pediatric gastroenterologists, nutritionists, and medical and surgical oncologists (Fig. 1). The text materials, animations, educational videos, and images were designed to serve a lay audience with a

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 Received for publication July 12, 2021; accepted July 17, 2022.

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 The authors declare no conflict of interest.

The *Animated Pancreas Patient—An Animated Patient's Guide to Pancreatic Diseases* is supported by unrestricted education grants from Abbvie Inc, Boston Scientific Corporation, Celgene Corporation, Ethicon US LLC, and Incyte Corporation. Mechanisms in Medicine, the developers of this resource, declare no conflict of interest in the development of the program.

Supplemental digital contents are available for this article. Direct URL citations appear in the printed text and are provided in the HTML and PDF versions of this article on the journal's Web site ([www.pancreasjournal.com](http://www.pancreasjournal.com)).

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DOI: 10.1097/MPA.0000000000002087

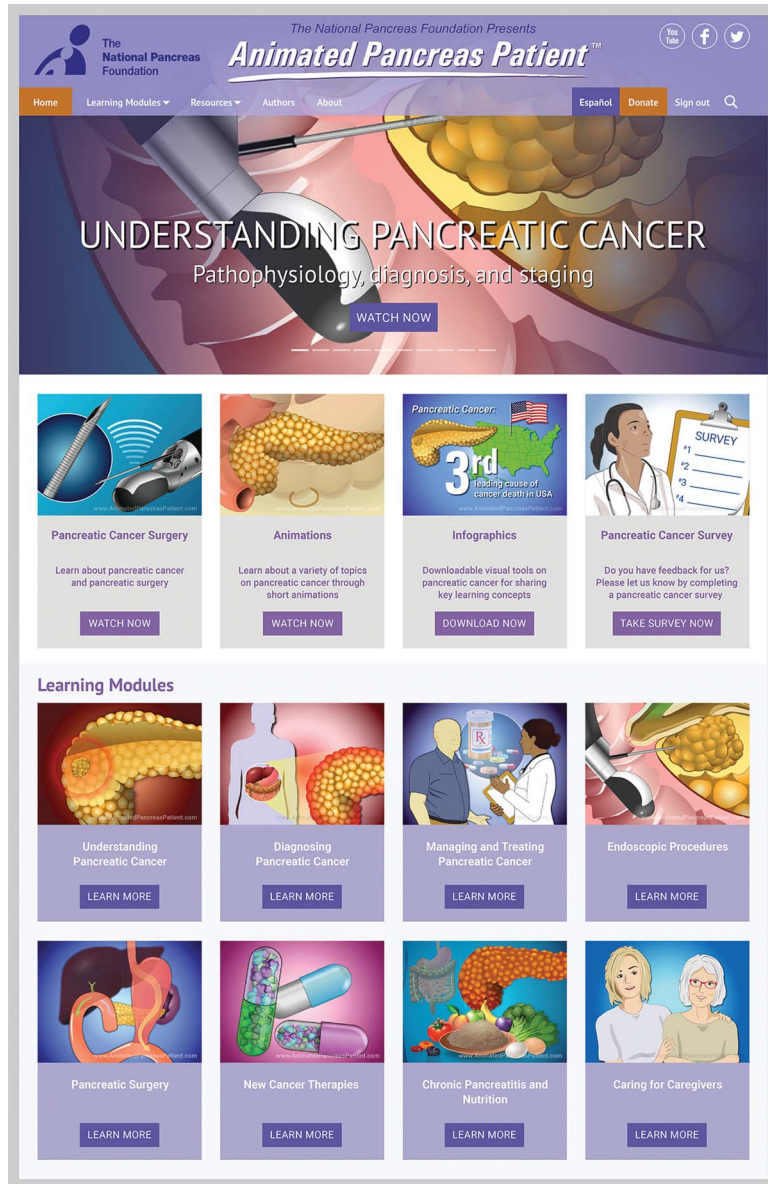


FIGURE 1. Animated Pancreas Patient website.

grade 6 to 8 literacy level (as assessed by literacy online evaluation tools). Each module is created to be succinct, practical, informative, evidence based, patient centric, and aligned with the chosen learning objectives (Table 1). Detailed description of the content development can be found elsewhere.<sup>14</sup>

The APP content contains PC animations, expert videos, and patient experience videos. Each of the animations and videos is developed to be viewed within a 3- to 7-minute timeframe. The APP education modules can be accessed directly from NPF's websites <https://pancreasfoundation.org> or <http://www.animatedpancreaspatient.com> or through the APP YouTube channel <https://www.youtube.com/user/ThePancreasPatient>. The list of available animations, expert videos, and patient experience videos is illustrated in Supplemental Table 1 (<http://links.lww.com/MPA/A968>). The APP

website homepage also prompts users to provide an optional feedback survey (Supplemental Table 2, <http://links.lww.com/MPA/A968>).

### User Metrics Measurement and Statistical Analysis

Data were reported as frequencies and proportion and mean (standard deviation) where appropriate. We evaluated audience reach, demographics, and metrics such as number of visit sessions, number of unique visitors, page views, duration of page views, and duration of video views for the APP website and the APP YouTube channel. We also calculated top views, top views by media type (animation, expert video, patient experience video, storyboard slide show), and top retention videos overall for the APP website and YouTube

**TABLE 1. Pancreatic Cancer Educational Content for the Animated Pancreas Program**

<b>Animations</b>
Pancreatic Cancer: Signs, Symptoms, and Risk Factors
Pancreatic Cancer: Pathophysiology, Diagnosis, and Staging
Pancreatic Cancer: Treatment and Outcomes
Understanding Clinical Trials
<b>Expert videos</b>
Pancreatic Cancer: Signs, Symptoms, and Risk Factors
What are the symptoms of pancreatic cancer?
How can I reduce my risk for developing pancreatic cancer?
Pancreatic Cancer: Pathophysiology, Diagnosis, and Staging
How is pancreatic cancer diagnosed?
What are the different stages of pancreatic cancer?
Pancreatic Cancer: Treatment and Outcomes
How is pancreatic cancer treated?
What is “curative treatment” for pancreatic cancer?
What is “palliative treatment” for pancreatic cancer?
What kinds of surgeries are performed to remove malignant pancreatic cancer tumors?
What should I expect following surgery to remove a malignant pancreatic cancer tumor?
Should I participate in a clinical trial?
What new advances are there in the treatment of pancreatic cancer?
<b>Clinical Trials</b>
What is a clinical trial?
Why are clinical trials important?
How do clinical trials work? How are they conducted?
What are the phases of clinical trials?
Who can participate in a clinical trial?
Why should a patient join a clinical trial?
What are some of the risks and benefits of volunteering for a clinical trial?
What is “informed consent” in a clinical trial?
What safeguards are in place to protect patients in clinical trials?
What happens if a patient changes their mind and wants to leave a clinical trial?
Will patients know or be able to pick what medications they will be receiving when they are in a clinical trial?
What is a “placebo” in a clinical trial and is it always used?
How will I find out about the results of a clinical trial?
What does “randomized,” “standard of care arm,” and “experimental arm” mean in a clinical trial?

channel. Finally, we assessed the educational impact of the APP cancer program from the feedback survey data.

**RESULTS**

**Participant Characteristics**

During the study period, the APP website and YouTube channel had 4,551,079 total views of which 423,758 views (9.3%) were for the PC modules (APP, 40,233; YouTube, 383,525). Overall, the educational content was accessed by 2,757,064 unique participants from 161 countries (54%, patients; 17%, family and caregivers; 16%, health care providers; and 13%, other). Most of the unique visitors (60%) to the APP website were from the United States, and the rest were from other countries (Fig. 2).

Of the 13,138 respondents who provided feedback, 7.4% (n = 973) provided feedback on PC. More than half of participant responses (54% identified as cancer patients; the rest were family or caregivers [17%], health care providers [16%], and other [13%]).

**Animations, Expert Videos, and Patient Videos**

Table 2 lists the most popular topics for the animations and videos. “Understanding Clinical Trials” (182,217 views), “Pancreatic Cancer: Treatment and Outcomes” (82,585 views), “Pancreatic Cancer: Signs, Symptoms, and Risk Factors” (64,970 views), and “Pancreatic Cancer: Pathophysiology, Diagnosis, and Staging” (27,471 views) were the top animations viewed, respectively.

The most common expert videos viewed by the participants were “What are the different stages of pancreatic cancer?” (15,357 views), “What are the symptoms of pancreatic cancer?” (12,475 views), “What is a “placebo” in a clinical trial and is it always used?” (5282 views), “What should I expect following surgery to remove a malignant pancreatic cancer tumor?” (3863 views), and “What is ‘informed consent’ in a clinical trial?” (2745 views) (Table 2).

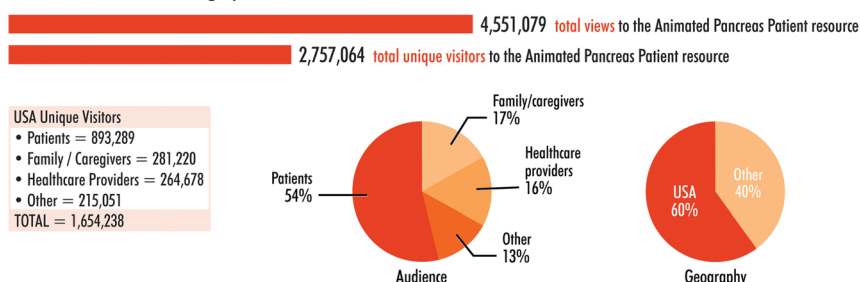
**Viewer Retention for Animations and Videos**

Table 3 lists the top 4 animations and top 10 videos by viewer retention (as determined by the percentage of the total video length viewed). On average, 51.78% of each video’s content was viewed.

**Participant Knowledge and Commitment to Change**

Among the 973 participants who completed the online feedback survey, approximately 91% reported that they learned new information, 85% learned new treatment options, and 82% learned new surgery options for PC. Most participants (94%) also expressed a commitment to change in terms of using the

**Audience Reach and Demographics**



**FIGURE 2.** Audience reach and demographics.

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**TABLE 2.** Top 4 Animations and Top 10 Expert Videos by Frequency

Video Type	Video Title	YouTube	APP	Total
Animations	Understanding Clinical Trials	180,845	1372	182,217
	Pancreatic Cancer: Treatment and Outcomes	77,942	4643	82,585
	Pancreatic Cancer: Signs, Symptoms, and Risk Factors	56,151	8819	64,970
	Pancreatic Cancer: Pathophysiology, Diagnosis, and Staging	23,112	4359	27,471
Expert videos	What are the different stages of pancreatic cancer?	14,869	488	15,357
	What are the symptoms of pancreatic cancer?	10,917	1558	12,475
	What is a “placebo” in a clinical trial and is it always used?	5206	76	5282
	What should I expect following surgery to remove a malignant pancreatic cancer tumor?	3624	239	3863
	What is “informed consent” in a clinical trial?	2701	44	2745
	What is “palliative treatment” for pancreatic cancer?	2337	353	2690
	How is pancreatic cancer diagnosed?	1402	528	1930
	What are the phases of clinical trials?	1385	38	1423
	How can I reduce my risk for developing pancreatic cancer?	535	809	1344
	How is pancreatic cancer treated?	186	554	740

information to better manage their PC and indicated their intention to engage with their doctor in discussions (Fig. 3).

## DISCUSSION

During the 7-year study period, the NPF's APP PC education modules garnered 423,758 views and approximately 320,284 unique participants. The most popular topic among the animations was “Understanding Clinical Trials” and the most common expert video viewed was “What are the different stages of pancreatic cancer?” Participants who completed the online feedback survey reported knowledge gains and commitment to change by engaging with their physician or implementing a newly learned self-management action.

Pancreatic cancer causes substantial morbidity, mortality, and costs. Although the efforts to improve PC outcomes are being pursued in areas related to prevention, early diagnosis, surveillance, and management, reliable educational resources specific to PC patient needs and understanding of disease are limited. Current cancer patient education resources and content are

predominantly text based<sup>15–23</sup> and most often written at literacy levels above the comprehension level of lay persons, even though National Institutes of Health and the American Medical Association recommends a fifth grade to eighth grade level for patient education materials.<sup>8,24</sup>

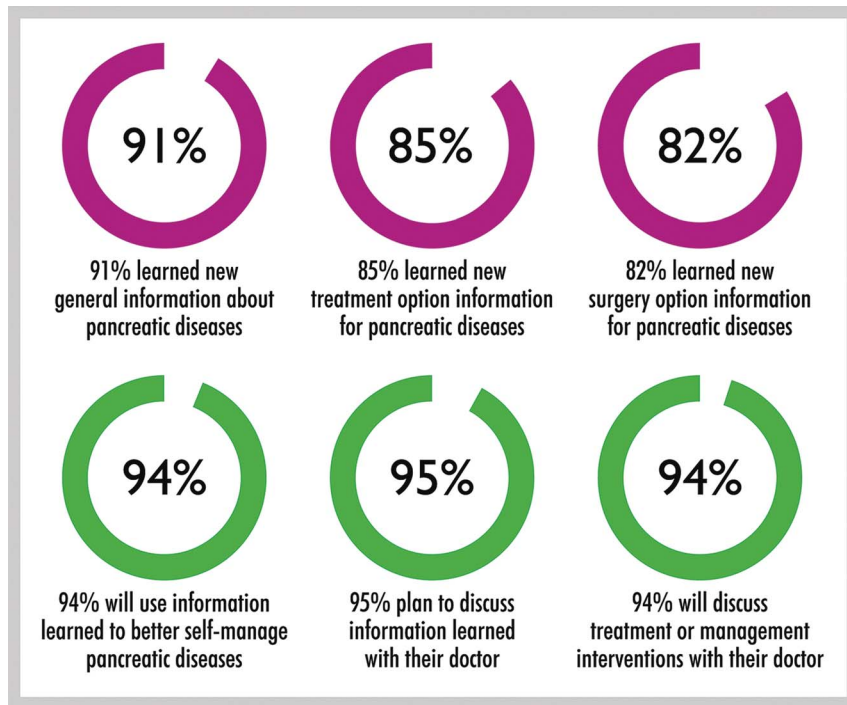
National Pancreas Foundation's *Animated Pancreas Patient—An Animated Patient's Guide to Pancreatic Diseases* uses visual formats of learning to address patient barriers to health literacy and provides accessible, easy-to-follow, evidence-based resources. Multidisciplinary expert faculty authors guide content development of the APP website resources. Educational content is simple to understand; brief animations with narration are easily understood focusing on frequently asked questions and key disease concepts. Short video segments of experts answering commonly asked questions complement learning tools; videos of patients sharing their disease experiences and downloadable slide shows add to the content covered by animations. The content of the education modules aligns with the health literacy literature on the effectiveness of visual aids and video formats in patient education.<sup>25</sup> The feedback survey on self-reported gains in learning,

**TABLE 3.** Top 4 Animations and Top 10 Expert Videos by Highest Retention\* Viewed

Video Type	Video Title	Average Percentage Viewed, %
Animations	Pancreatic Cancer: Signs, Symptoms, and Risk Factors	68.2
	Pancreatic Cancer: Pathophysiology, Diagnosis, and Staging	63.9
	Pancreatic Cancer: Treatment and Outcomes	60.2
	Understanding Clinical Trials	48.4
Expert videos	How is pancreatic cancer diagnosed?	70.5
	Why are clinical trials important?	64.4
	How can I reduce my risk for developing pancreatic cancer?	63.0
	What is “curative treatment” for pancreatic cancer?	62.5
	What are the symptoms of pancreatic cancer?	62.2
	What does “randomized,” “standard of care arm,” and “experimental arm” mean in a clinical trial?	61.5
	Can patients choose the medications they will receive in a clinical trial?	59.4
	Why should a patient join a clinical trial?	57.9
	What are the different stages of pancreatic cancer?	56.8
	What is a “placebo” in a clinical trial and is it always used?	54.7

\*Retention determined by the percentage of the total video length viewed.





**FIGURE 3.** Patients who experienced improved outcomes.

competence, and intention to change also align with Moore and colleagues<sup>26</sup> and is consistent with level 4 outcomes for continuing medical education. This unique format of learning permits feedback from learners through voluntary self-evaluation tools and encourages learners to indicate benefits in knowledge acquisition; learners indicate their intent to discuss an intervention with their oncology provider, and the APP format elicits and reports on improved learner understanding. Educational content helps learners make informed choices and share in decisions with their health care providers in PC management.

Some of the strengths of our study assessed over a period of 7 years include wide reach of this program (US and global audience), use of a multidisciplinary expert faculty in the development of content, addressing health literacy impediments, and improving understanding related to PC patient needs. Patients are able to participate in shared decisions gained through APP educational modules, which promote patient satisfaction with their health care experience.<sup>27,28</sup> Educational animations and content are continuously being added, and the translation of the English program into Spanish is now available at [www.PancreasAnimado.com](http://www.PancreasAnimado.com). Other language programs to benefit global communities with PC are feasible future opportunities.

The limitations of our study include retrospective design and a relatively small group of users taking part in the optional feedback survey. Although the APP received approximately 4.5 million views worldwide, only few ( $n = 13,138$ ) participated in the feedback survey. This is because the feedback survey was optional (no monetary compensation is provided) for completing the survey. The program also lacked a formal presurvey/postsurvey assessment. Because of the nature of the feedback survey, we were limited in gathering in-depth learner data, and future goals are to improve the quality of information from diverse learner audiences. Our results may be biased because the metrics were evaluated from among those who had access to modules through APP website and YouTube only. Access to online learning requires

technology access, which may vary by cultural, demographic, and socioeconomic differences.

In conclusion, *Animated Pancreas Patient—An Animated Patient's Guide to Pancreatic Diseases* using visual formats of learning demonstrates wide reach and has vast potential to improve understanding and benefit health outcomes by informing PC patients, families, and caregivers.

Continued efforts should be made to provide patient resources that address health literacy barriers, increase understanding of PC, and improve health outcomes and quality of life.

#### ACKNOWLEDGMENTS

*The authors thank Mechanisms in Medicine Inc for the website programming and developed, video production, metrics reporting and animation development of the Animated Pancreas Patient—An Animated Patient's Guide to Pancreatic Diseases.*

#### REFERENCES

1. The American Cancer Society medical and editorial content team. How common is pancreatic cancer? Key statistics for pancreatic cancer. Available at: <https://www.cancer.org/cancer/pancreatic-cancer/about/key-statistics.html>. Accessed June 7, 2021.
2. Peery AF, Crockett SD, Barritt AS, et al. Burden of gastrointestinal, liver, and pancreatic diseases in the United States. *Gastroenterology*. 2015;149:1731–1741.e3.
3. U.S. National Institutes of Health, National Cancer Institute. SEER: Cancer Stat Facts: Pancreatic Cancer, 2011–2017. Available at: <https://seer.cancer.gov/statfacts/html/pancreas.html>. Accessed June 7, 2021.
4. Singh S, Singh PP, Singh AG, et al. Anti-diabetic medications and risk of pancreatic cancer in patients with diabetes mellitus: a systematic review and meta-analysis. *Am J Gastroenterol*. 2013;108:510–519; quiz 520.
5. Berkman ND, Sheridan SL, Donahue KE, et al. Low health literacy and health outcomes: an updated systematic review. *Ann Intern Med*. 2011;155:97–107.

6. Levy H, Janke A. Health literacy and access to care. *J Health Commun.* 2016;21(suppl 1):43–50.
7. Hersh L, Salzman B, Snyderman D. Health literacy in primary care practice. *Am Fam Physician.* 2015;92:118–124.
8. Weiss BD. *Health Literacy and Patient Safety: Help Patients Understand. Manual for Clinicians.* 2nd ed. Chicago, IL: American Medical Association Foundation; 2007.
9. Institute of Medicine (US); Board on Neuroscience and Behavioral Health; Committee on Health Literacy; Nielsen-Bohman L, Panzer AM, Kindig DA, eds. What is health literacy? In: *Health Literacy: A Prescription to End Confusion.* Washington, DC: National Academies Press (US); 2004.
10. Halverson JL, Martinez-Donate AP, Palta M, et al. Health literacy and health-related quality of life among a population-based sample of cancer patients. *J Health Commun.* 2015;20:1320–1329.
11. Busch EL, Martin C, DeWalt DA, et al. Functional health literacy, chemotherapy decisions, and outcomes among a colorectal cancer cohort. *Cancer Control.* 2015;22:95–101.
12. The National Pancreas Foundation. 2021. Available at: <https://pancreasfoundation.org/>. Accessed February 1, 2021.
13. Animated Pancreas Patient. 2021. Available at: <http://www.animatedpancreaspatient.com>. Accessed February 1, 2021.
14. Munigala S, Gardner TB, O'Reilly EM, et al. Understanding pancreatic diseases using animated pancreas patient informing patients for better health outcomes with visual formats of learning. *Pancreas.* 2018;47:1256–1261.
15. National Comprehensive Cancer Network. NCCN Guidelines for Patients: Pancreatic Cancer (Version 1.2017). Available at: <https://www.nccn.org/guidelines/guidelines-detail?category=patients&id=33>. Accessed February 1, 2021.
16. Storino A, Castillo-Angeles M, Watkins AA, et al. Assessing the accuracy and readability of online health information for patients with pancreatic cancer. *JAMA Surg.* 2016;151:831–837.
17. Prabhu AV, Hansberry DR, Agarwal N, et al. Radiation oncology and online patient education materials: deviating from NIH and AMA recommendations. *Int J Radiat Oncol Biol Phys.* 2016;96:521–528.
18. Prabhu AV, Donovan AL, Crihalmeanu T, et al. Radiology online patient education materials provided by major university hospitals: do they conform to NIH and AMA guidelines? *Curr Probl Diagn Radiol.* 2018;47:75–79.
19. Prabhu AV, Crihalmeanu T, Hansberry DR, et al. Online palliative care and oncology patient education resources through Google: do they meet national health literacy recommendations? *Pract Radiat Oncol.* 2017;7:306–310.
20. Hansberry DR, Agarwal N, John ES, et al. Evaluation of internet-based patient education materials from internal medicine subspecialty organizations: will patients understand them? *Intern Emerg Med.* 2017;12:535–543.
21. Weiss KD, Vargas CR, Ho OA, et al. Readability analysis of online resources related to lung cancer. *J Surg Res.* 2016;206:90–97.
22. Hansberry DR, Patel SR, Agarwal P, et al. A quantitative readability analysis of patient education resources from gastroenterology society websites. *Int J Colorectal Dis.* 2017;32:917–920.
23. Prabhu AV, Kim C, Crihalmeanu T, et al. An online readability analysis of pathology-related patient education articles: an opportunity for pathologists to educate patients. *Hum Pathol.* 2017;65:15–20.
24. U.S. National Institutes of Health. Clear Communication. Clear and Simple. Available at: <https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication/clear-simple>. Accessed February 1, 2021.
25. Nienkamp M. Visual learning tools overcome health illiteracy. [PSQH e-Newsletter]. July–August 2006. Available at: <https://www.psqh.com/julaug06/visual.html>. Accessed February 1, 2021.
26. Moore DE Jr, Green JS, Gallis HA. Achieving desired results and improved outcomes: integrating planning and assessment throughout learning activities. *J Contin Educ Health Prof.* 2009;29:1–15.
27. Kane HL, Halpern MT, Squiers LB, et al. Implementing and evaluating shared decision making in oncology practice. *CA Cancer J Clin.* 2014;64:377–388.
28. Katz SJ, Hawley S. The value of sharing treatment decision making with patients: expecting too much? *JAMA.* 2013;310:1559–1560.