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Readability assessment of online gynecologic oncology patient education materials from major governmental, non-profit and pharmaceutical organizations

David Samuel [a,*], Nicole Vilardo [a], Sara S. Isani [a,b], D.Y.S. Kuo [a,b], Gregory M. Gressel [a,b]

[a] Montefiore Medical Center and Albert Einstein College of Medicine, Department of Obstetrics & Gynecology and Women's Health, Bronx, NY, United States of America
[b] Albert Einstein Cancer Center, Albert Einstein College of Medicine, Bronx, NY, United States of America

HIGHLIGHTS

- Patients are increasingly using online resources as a trusted source of health information.
- Online gynecologic oncology PEMs are written well above the recommended sixth to eighth grade reading level.
- PEMs from pharmaceutical companies are less complex than those from governmental agencies and nonprofit organizations.
- Simplifying PEMs may improve patient understanding of their disease and facilitate physician-patient communication.

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ABSTRACT

Objective. Patients are increasingly using online materials to learn about gynecologic cancer. Providers can refer patients to online educational materials produced by a number of different major medical organizations and pharmacology companies. The National Institutes of Health (NIH) and the American Medical Association (AMA) recommend that patient educational materials (PEMs) are written between a sixth and eighth grade reading level. In this study, we assess the readability of online PEMs published by major medical organizations and industry partners.

Methods. Websites from twelve websites providing educational materials for gynecologic oncology patients were surveyed. Online PEMs were identified and analyzed using seven validated readability indices. One-way ANOVA and Tukey's Honestly Significant Difference (HSD) post-hoc analysis were performed to detect differences in readability between publishers.

Results. Two-hundred and sixty PEMs were included in this analysis. Overall, PEMs were written at a mean 11th ± 0.6 grade reading level. Only 6.5% of articles were written at the AMA/NIH recommended reading grade level of 6th to 8th grade or below. ANOVA demonstrated a significant difference in readability between publishing associations ($p < 0.01$). PEMs from the Centers for Disease Control had a mean 9th ± 1.2 grade reading level and were significantly lower than all other organizations. PEMs from The Foundation for Women's Cancer had a mean 13th ± 1.8 grade reading level and were significantly higher than most other organizations. PEMs from pharmaceutical companies (mean readability = 10.1 ± 1.1, $N = 30$) required the lowest reading grade level and were significantly more readable than those from governmental organizations (11.1 ± 1.7, $p < 0.05$) and nonprofit medical associations (12.4 ± 1.7, $p < 0.01$) in ANOVA and Tukey-Kramer post hoc analysis.

Conclusions. Gynecologic oncology PEMs available from twelve major organization websites are written well above the recommended sixth to eighth grade reading difficulty level.

1. Background

Women with gynecologic cancers are well-represented as users of online resources and use them to help make decisions affecting their healthcare. In fact, 85% of patients with a gynecologic malignancy utilize the Internet as a health information resource and there are nearly 2 million monthly online searches related to gynecologic oncology [1,2].

* Corresponding author at: 1300 Morris Park Ave, Block Bldg Rm 628, Bronx, NY 10461, United States of America.
E-mail address: dsamuel@montefiore.org (D. Samuel).

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Most commonly, cancer patients use online sources to research treatments and management of adverse effects associated with treatment [1]. Online searches by patients have a significant impact on their medical decision making. In a recent survey, 70% of those who used online health information reported it influenced their decision about how to treat an illness. Moreover, 50% reported Web information led them to ask their physician new questions or get a second opinion [3].

While online PEMs can empower patients to be active participants in their gynecologic cancer care, poorly written or complex health information may have negative effects on patient understanding [4–6]. In particular, misinformation may lead patients to avoid appropriate care due to fear or lack of understanding of health information.

The average American adult reads between an eighth and ninth grade reading level [7]. However, approximately 90 million adults have "fair" to "poor" literacy and 21–23% of adults read at the fifth-grade reading level or lower [7]. Patients whose primary language is not English, as well as older adults with cognitive decline or sensory deficits face additional literacy challenges [8]. Beyond the ability to read and write, health literacy is a more complex skill defined as the ability to gather, interpret, act on, and communicate healthcare information [9]. While literacy includes reading, numeracy and graphical skills, health literacy is the application of these to participate in healthcare. Poor health literacy has been associated with numerous adverse healthcare outcomes such as decreased utilization of preventative services, decreased cancer screening, increased healthcare costs, diagnosis at later cancer stage and higher mortality [10,11].

To account for the average American literacy, the National Institutes of Health (NIH) and American Medical Association (AMA) recommend that PEMs are written at or below a sixth to eighth grade reading level [12,13]. Little is known about the readability of online PEMs related to gynecologic cancer and how different publishing organizations compare. The purpose of this study is to assess the readability of online gynecologic oncology PEMs published by medical associations and industry stakeholders and determine if they meet guidelines for reading complexity level.

2. Methods

In August 2018, gynecologic oncology PEMs from twelve major medical organizations and industry partners were identified. We selected national organizations involved in advancing awareness of gynecologic cancers and publishing scientific research, evidence-based guidelines and other reliable healthcare information commonly referenced by obstetrician-gynecologists or gynecologic oncologists. Pharmaceutical companies producing drugs with a Food and Drug Administration indication for treatment of gynecologic cancer or who produced drugs otherwise commonly used in gynecologic oncology were also included. Organization websites were then reviewed to identify PEMs. We defined PEMs as documents that met the following criteria: discussed a topic in gynecologic oncology with an educational focus, were directed to patients, written in English, available for free, were not published by news-media and did not contain multimedia.

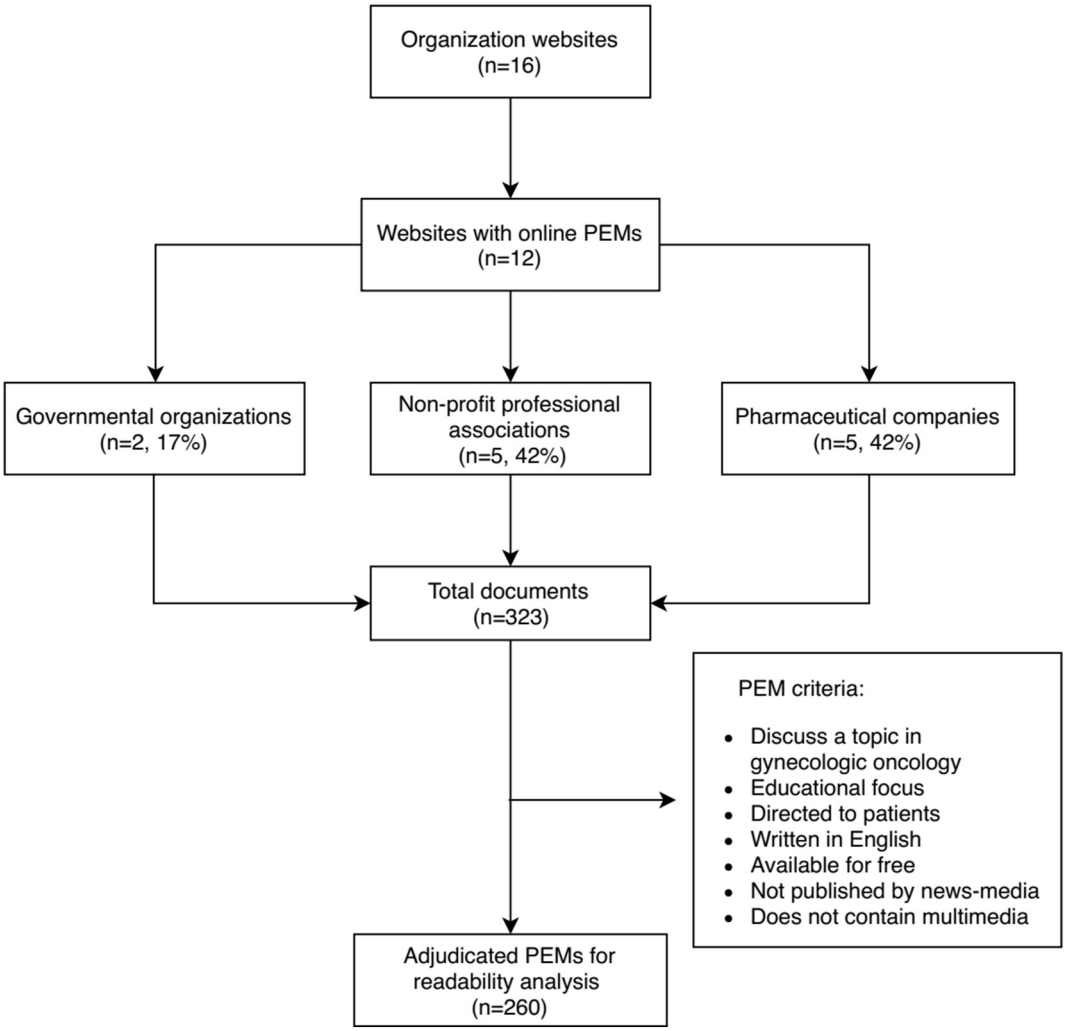

Fig. 1. Flowchart demonstrating selection and adjudication process for identification and inclusion of gynecologic oncology patient education materials (PEMs) for readability assessment.

Table 1
Number of gynecologic oncology patient education materials (PEMs) from each medical organization assessed for readability.

Association	# of PEMs
American College of Obstetrics and Gynecology (ACOG)	13
Centers for Disease Control and Prevention (CDC)	31
Clovis Oncology	3
Foundation for Women's Cancer (FWC)	31
Genentech	4
Janssen	7
Merck	11
National Cancer Institute (NCI)	73
National Cervical Cancer Coalition (NCCC)	14
National Ovarian Cancer Coalition (NOCC)	22
Society of Gynecology Oncology (SGO)	46
Tesaro	5
Overall	**260**

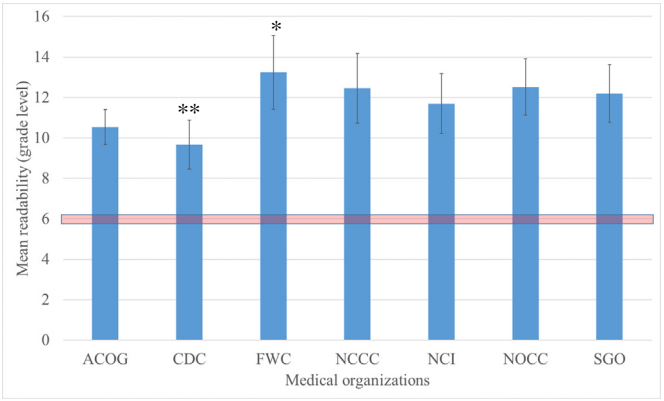

Fig. 2. Readability of patient education materials (PEMs) from major medical organizations. Means are reported with standard deviation as error bars. *FWC PEMs were the most complex (grade-level 13.2 ± 1.8, $N = 13$) and were significantly higher than PEMs from ACOG, CDC, NCI and SGO ($p < 0.01$). ** PEMs published by the CDC were written at the lowest reading level (grade level 9.7 ± 1.2, $N = 26$) and were significantly lower than PEMs from all other organizations except ACOG ($p < 0.01$). SGO, NCI, NCCC, NOCC did not have a significantly different reading level in all pairwise combinations.

Those organization websites who maintained PEMs meeting these definitional criteria were included in the analysis. The American College of Obstetrics and Gynecology (ACOG), Centers for Disease Control and Prevention (CDC), Clovis Oncology, Foundation for Women's Cancer (FWC), Genentech, Janssen, Merck, National Cancer Institute (NCI), National Cervical Cancer Coalition (NCCC), National Ovarian Cancer Coalition (NOCC), the Society of Gynecologic Oncology (SGO) and Tesaro were included. Organization websites were browsed and PEMs were downloaded to a database. Within PEMs, non-medical content such as copyright notices, authors, disclaimers, web navigation links and references were excluded from the readability analysis. Figures and their captions were also excluded.

Quantitative readability assessments were performed using Readability Studio (version 2015.1, Oleander Software Ltd., Vandalia, OH). Readability was defined as the school-grade level of literacy needed to understand a PEM. Scores below 9 suggest a middle school or lower level of literacy is required for comprehension. PEMs scoring >12 would require a post-high school level of literacy. PEMs were analyzed using six validated readability metrics: Coleman-Liau index [14], Flesch-Kincaid Grade Level [15], FORCAST formula [16], Gunning Fog Index [17], New Dale-Chall formula [18], and Simple Measure of Gobbledygook (SMOG) formula [19]. A graphical assessment, the Fry Readability Graph [20] was also used. These metrics use characteristics such as sentence length, number of words per sentence, number of characters per word, and number of syllables per word to determine text complexity [2,21–25].

After calculating mean readability level of PEMs from each organization, PEMs were then further divided by publisher funding source. The CDC and NCI are governmental organizations as they are federal agencies under the Department of Health and Human Services. ACOG, FWC, NCCC, NOCC, and SGO were classified as nonprofit medical associations since they are non-governmental organizations advocating for patients with gynecologic malignancies or physician professional societies. Pharmaceutical companies with online PEMs on gynecologic cancer were also identified including Janssen Pharmaceutica, Clovis Oncology, Merck & Co, Inc., Genentech, Inc., and Tesaro, Inc. Statistical differences between publishing organizations were measured using one-way analysis of variance (ANOVA) test and confirmed using the Tukey-Kramer post-hoc test. All statistical analysis was performed using SPSS (version 22, IBM, Armonk, NY). Significance level was set at $p < 0.05$.

3. Results

A total of 260 PEMs from twelve major organizations were included in this analysis (Fig. 1, Table 1). Collectively, these PEMs were written at a mean 11th grade ± 0.6 reading level across all readability metrics (Table 2). PEMs were written between 7 and 16.8 grade levels, with the highest requiring a graduate-school reading level. The mean readability grade levels for the entire cohort of PEMs was 11.5 ± 2.2 for Coleman-Liau index; 10.8 ± 2.4 for Flesch-Kincaid Grade Level; 11.3 ± 0.9 for FORCAST formula; 11.9 ± 2.5 for Gunning Fog Index; 11.3 ± 2.4 for New Dale-Chall formula; and 12.7 ± 1.9 for SMOG formula

Table 2
Readability algorithms used to analyze gynecologic oncology patient education materials (PEMs).

Readability test	Formula	Variables
Coleman-Liau Index	**CLI** = (0.0588 × L) − (0.296 × S) − 15.8 *Average letters per 100 words (L)and average number of sentences per 100 words (S)*	Characters Words Sentences
Flesch Kincaid Grade Level	**FKGL** = (0.39 × W) + (11.8 × S) − 15.59 *Average words per sentence (W) and average number of syllables per word (S)*	Syllables Words Sentences
FORCAST Formula	**FORCAST** = 20 − (SS/10) *Number of single-syllable words in a 150-word sample (SS)*	Syllables Words
Fry Graph	*Average number of sentences per 100 words* vs *syllables per 100 words, plotted on Fry graph.*	Syllables Sentences
Gunning Fog Index	**GFI** = 0.4 × (W/S + 100(C/W)) *Number of Sentences (S), number of words (W), number of words with three or more syllables (C)*	Syllables Words Sentences
New Dale Chall Formula	**NDC** = (0.1579 × D%) + (0.0496 × W/S) *Number of words (W), number of sentences (S) and percent difficult words from standard list (D%)*	Words Sentences Difficult words
SMOG Formula	**SMOG** = 1.043 × Sqrt (P × (30/S)) + 3.1291 *Average number of words with 3 or more syllables (P) and average number of sentences (S)*	Polysyllabic words Sentences

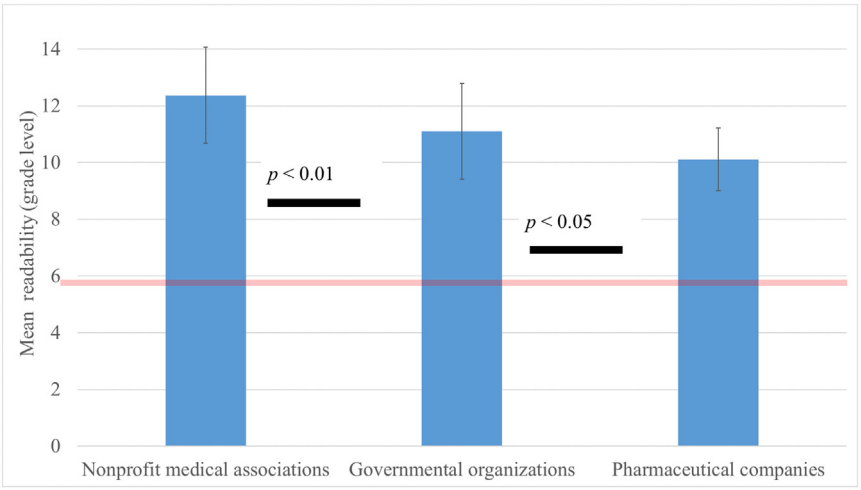

Fig. 3. Readability comparison of patient education materials by organization funding source. Patient education materials from pharmaceutical companies required the lowest reading level (10.1 ± 1.1, $N = 30$). They were significantly lower than those from governmental organizations ($p < 0.05$) and nonprofit medical associations ($p < 0.01$).

(Supplemental Fig. 1). The Fry Readability Graph also demonstrated the majority of PEMs were written well above the recommended readability levels (Figs. 2–3). Only 6.5% of PEMs were written at the AMA/NIH recommended criteria of below an eighth-grade reading level. In addition, 21.9% of PEMs required a college education or higher level of reading for comprehension. Overall, PEMs had an average of 17.2% of complex words (>3 syllables) and 35.9% of long words (>6 characters).

PEMs from each organization were evaluated. The CDC had the lowest mean readability grade level of 9.7 ± 1.2 and 9 of the 31 PEMs met NIH/AMA criteria. PEMs from the FWC had the highest mean readability grade level of 13.2 ± 1.8, and none of the 31 PEMs met NIH/AMA criteria. Mean readability grade levels for other organizations were: $10.5 + 0.9$ for ACOG, 11.7 ± 1.5 for NCI, 12.5 ± 1.7 for NCCC, 12.5 ± 1.4 for NOCC, and 12.2 ± 1.4 for SGO. Of these associations, only 3 of 198 PEMs were written at or below an eighth grade reading level.

One-way ANOVA demonstrated significant differences in readability between publishing organizations ($p < 0.01$). This was confirmed with Tukey-Kramer post-hoc analysis in pairwise comparisons. The CDC's PEMs (mean readability $= 9.7 \pm 1.2$) were written at a significantly lower grade level than all other associations ($P < 0.01$), except ACOG (10.5 ± 0.9). Moreover, FWC's PEMs (mean readability $= 13.2 \pm 1.8$) required a significantly greater reading grade level than PEMs from ACOG (10.5 ± 0.9, $p < 0.01$) CDC (9.7 ± 1.2, $p < 0.01$), NCI (11.7 ± 1.5, $p < 0.01$), and SGO (12.2 ± 1.4, $p < 0.05$). There were no statistically significant differences in readability in PEMs from SGO, NCI, NCCC, and NOCC in all pairwise comparisons.

Compared with PEMs from governmental organizations and nonprofit medical associations, PEMs from pharmaceutical companies (mean readability $= 10.1 \pm 1.1$, $N = 30$) required the lowest reading grade level and 13.3% were written at the NIH/AMA recommended level. They were significantly more readable than PEMs from governmental organizations (11.1 ± 1.7, $p < 0.05$) and nonprofit medical associations (12.4 ± 1.7, $p < 0.01$) in ANOVA and Tukey-Kramer post hoc analysis. Nonprofit medical associations published PEMs requiring the highest reading grade level (mean readability $= 12.4 \pm 1.7$, $N = 126$). Only 2 of these 126 PEMs met NIH/AMA criteria for readability. One-way ANOVA and Tukey-Kramer post hoc test showed PEMs from nonprofit medical associations were significantly less readable than those from governmental organizations ($p < 0.01$) and pharmaceutical companies ($p < 0.01$).

4. Discussion

Our findings demonstrate that gynecologic oncology PEMs from twelve major organizations including governmental bodies, nonprofit medical associations and pharmaceutical companies are written well above the comprehension level of the average American, requiring a mean 11th grade reading level for appropriate understanding. In fact, only 7% of the 260 PEMs met the NIH/AMA criteria and 22% required of PEMs required a college level of reading comprehension (Fig. 2). This finding has been corroborated in numerous other studies of educational literature for other oncologic disease sites [4,26–29].

When stratified by organization type, there were differences in readability between governmental organizations, nonprofit medical associations and pharmaceutical companies. Interestingly, PEMs from nongovernmental organizations and professional medical societies such SGO, ACOG and FWC were the least readable and required a 12th grade reading level for comprehension (Fig. 3). Only 2 of 126 PEMs in this category met NIH/AMA criteria. PEMs from pharmaceutical companies were the easiest to read and significantly easier than those from nonprofit medical associations and governmental organizations (Fig. 3). PEMs from medical groups may place greater emphasis on medically complex topics like diagnosis, treatment efficacy, and risks and adverse effects which are intrinsically more difficult to read. However, facile readability of pharmaceutical PEMs could also reflect direct marketing of these materials to patients. Pharmaceutical companies have a direct financial interest in patients understanding their disease and which pharmacologic agents they can receive.

Online PEMs serve as an important source of health information for many patients, who rate online health information as their second most valued resource when making health decisions, behind communication with their physician [30]. Online PEMs can also provide supplementary information to traditional physician counseling. One study reported 72% of patients who discussed online health information with their physician noticed a positive impact on the physician-patient relationship [31]. However, these effects are limited by patient comprehension of the material. A national survey conducted by the U.S. Department of Education reported that the average American reads at the 7th–8th grade reading level with only 12% of Americans demonstrating proficient health literacy [7]. Our findings highlight that PEMs from all studied organization types including professional society websites that gynecologic oncologists are perhaps most likely to refer patients to do not meet the NIH/AMA recommendations for reading difficulty level [12,13]. This may limit patients' ability to interpret PEMs and impede patient counseling, informed consent, compliance, satisfaction and participation in their own care.

Previous studies of online health information on non-gynecologic malignancies including urologic, pancreatic, colorectal, skin and lung cancers have revealed that PEMs in these diseases are also written at a highly complex level [4,26–29]. Given the lack of regulation and

Table 3
ACOG recommendations for improving readability of patient education materials. Adapted from ACOG Committee Opinion No 676. Health literacy to promote quality of care. *Obs Gynecol.* 2016;128:183–186.

- Keep the messages simple.
- Limit the number of messages (the general guideline is four main messages).
- Focus on action. Give specific recommendations based on behavior rather than the medical principle.
- Use the active voice instead of the passive voice.
- Use familiar language and avoid jargon.
- Use visual aids, such as drawings or models, for key points. Make sure the visual messages are culturally relevant.
- Use at least a 12-point type size to make the messages easy to read.
- Leave plenty of white space around margins and between sections.

heterogeneity of quality of online websites, gynecologic oncologists should familiarize themselves broadly with information available online that patients may be reading and provide them with reliable websites they can access for accurate information. Time should be allowed for patients to ask questions about PEMs in subsequent encounters and to verify patient understanding. The patient's age, education level, primary language, culture, independence in activities of daily living, insight into disease status and any cognitive or sensory deficits should be considered to individualize PEMs to the patient's literacy level.

A previous study evaluated the readability of top online search engine results for gynecologic oncology keywords and found they were written at a mean 9th grade reading level, using the SMOG formula [2]. However, our study is the first multi-metric readability analysis of PEMs published by major medical organizations. Our data highlight the need for improvement of existing gynecologic oncology PEMs. The Institute of Medicine recommends that healthcare organizations promote health literacy by providing patients with information that is easy to navigate, understand, and use [32]. In 2016, ACOG issued a committee opinion addressing health literacy and how to design easy to read patient materials [33]. Recommendations include keeping messages simple, using readable text size and focusing on patient behavior rather than medical principle and are detailed in Table 3. Once PEMs are formulated, they should be evaluated by a sample of the target audience to determine ease of understanding. Finally, software to test readability metrics are readily available and should be used to identify documents that are difficult to read for revision.

Several limitations of the study should be noted. Firstly, our assessment is limited by rote analysis of text to determine readability. For instance, medical terminology that is syllabically simple such as “vulvar,” “Pap smear,” “pelvic”, and “rectal” may be considered less complex, while lengthy words, such as “depression” and “overweight,” that are common, well-understood terms may be considered more complex based on number or characters or syllables. Conversely, if a complex term, such as “endometrial” or “gynecologic” is defined and explained, further instances are still considered difficult and will worsen the readability score. Seven validated readability scales were used to minimize such biases of each individual test. Our study was also limited by inability to assess audio and visual supplements, which may significantly contribute to patient understanding. Visual features which might make a patient more or less likely to read a document such as text size, font, density of text and white space could not be evaluated. Lastly, while our study assesses reading difficulty based on syntax, it does not assess the accuracy or relevance of the educational information provided. Further studies which include expert review of PEM content are needed.

Gynecologic oncology PEMs from medical organizations are written at levels too complex for the average American patient. The internet has changed how patients access healthcare information. Data from national surveys shows that health professionals remains the first choice for healthcare information for most Americans [34]. However, patients are increasingly turning to the Internet to facilitate understanding of their diagnoses and treatments, so it is important for medical organizations to develop an online presence that provides PEMs that are easy to read. Doing so may facilitate patient counseling, encourage active participation in their cancer care and improve the patient-physician relationship.

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ygyno.2019.06.026.

Author contributions

Dr. Samuel is the primary author on this study. He was responsible for the data collection, statistical analysis and compilation of the manuscript.

Dr. Vilardo aided with collection of the data and editing of the final manuscript.

Dr. Isani provided substantial contributions to the editing of the final manuscript.

Dr. Kuo provided substantial contributions to the editing of the final manuscript.

Dr. Gressel is the senior author on this study. He provided mentorship to Dr. Samuel in the study conception, design and execution and aided in editing the final manuscript.

Declaration of Competing Interest

The authors of this study have no relevant conflicts of interest to report.

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