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Communicating Critical Information to Cancer Survivors: An Assessment of Survivorship Care Plans in Use in Diverse Health Care Settings

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Abstract

Purpose: Survivorship care plans (SCPs) serve to communicate critical information needed for cancer survivors' long-term follow-up care. The extent to which SCPs are tailored to meet the specific needs of underserved patient populations is understudied. To fill this gap, this study aimed to assess the content and communication appropriateness of SCPs collected from diverse health care settings.

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Informed consent: No human participants were involved in this study for informed consent to be obtained.

Methods: We analyzed collected SCPs (n=16) for concordance with Institute of Medicine (IOM) recommendations for SCP content and for communication appropriateness using the Suitability Assessment of Materials (SAM) instrument.

Results: All plans failed to incorporate all IOM criteria, with the majority of plans (n=11) incorporating less than 60% of recommended content. The average reading grade level of all the plans was 14, and only one plan received a superior rating for cultural appropriateness.

Conclusion: There is significant variation in the format and content of SCPs used in diverse hospital settings and most plans are not written at an appropriate reading grade level nor tailored for underserved and/or minority patient populations.

Implications for Cancer Survivors: Co-designing SCPs with diverse patient populations is crucial to ensure that these documents are meeting the needs and preferences of all cancer survivors.

Keywords

Cancer survivorship; survivorship care plans; patient education; health communication; content analysis

Introduction

There are currently an estimated 15.5 million cancer survivors in the U.S [1]. This number is projected to increase by 70% in the next two decades due to advances in early detection, improved survival rates [2], and an aging population [3]. Cancer survivors face many unique challenges, including late and long-term health effects, emotional and financial hardships, and a greater risk for developing second cancers and other serious health conditions. There is evidence that these challenges are even greater among minority and underserved patients, including low income and uninsured patients, and those with low health literacy or limited English proficiency [4–6].

In 2005, the Institute of Medicine (IOM) recommended the widespread implementation of survivorship care plans (SCPs) to facilitate the transition from active treatment to cancer survivorship, as well as from oncology care to primary care [7]. SCPs encompass a summary of cancer treatment, which can be shared with current and future medical providers; a follow-up care plan incorporating available evidence-based standards of care; and information about available resources relating to medical and psychological survivorship needs. The stated purpose of SCPs in the IOM report is to communicate critical information needed for survivors' long-term care to help patients share in the responsibility for their health and to improve the coordination and quality of follow-up cancer care. The IOM recommendations call for oncology treatment teams to review SCPs with patients at the conclusion of their active cancer treatment, prior to transitioning back to primary care. The intention is for patients to keep the SCPs over time and share them with primary care and other providers.

In the years since the IOM recommended the implementation of SCPs, researchers have explored the content and use of SCPs among well-known cancer treatment facilities,

such as National Cancer Institute (NCI)-designated cancer centers [8], and LIVESTRONG Survivorship Centers of Excellence [9, 10]. These flagship cancer centers were likely to have sufficient resources to devote to the early development and implementation of new approaches to care delivery, such as SCPs. Outside of these settings, Behavioral Risk Factor Surveillance System (BRFSS) cancer survivorship modules suggest that patients with higher income were more likely to receive written or printed follow-up care instructions [11]. However, the extent to which SCPs are in use more broadly in diverse hospital settings around the country and tailored to meet the specific needs of diverse, underserved patient populations remains comparatively understudied.

To better understand the content of SCPs used in varied health care settings in the U.S., especially in relation to vulnerable patient populations that face disparities in cancer care, we collected SCPs from diverse health care delivery sites in two distinct geographic locations in the U.S. and performed a content analysis. We aimed to explore differences in plans by hospital setting, including those that treat primarily underserved patient populations, and better-resourced health care settings, such as academic medical centers.

Methods

SCP collection

We employed a purposive sampling strategy for collection of SCPs in two geographic locations of the United States—the Midwestern and Western regions of the country. We targeted collection of SCPs from a diverse range of hospital settings, including safety-net health systems, community hospitals, academic health centers, and integrated delivery systems (IDSs). For the purpose of this study, safety-net health systems are defined as hospitals that serve primarily uninsured, Medicaid, and other vulnerable patient populations; community hospitals are independently run, non-profit hospitals that serve a local community; academic health centers are university-based teaching hospitals affiliated with medical schools; and IDSs are networks of vertically integrated health care organizations that coordinate services across the care continuum. We include VA hospitals in our category of IDSs, which are federal medical centers operated by the U.S. Department of Veterans Affairs to serve the needs of Veterans, including those with disabilities and those without insurance.

We focused on collecting SCPs for breast and colorectal cancer survivors, as these are two highly prevalent cancers for which SCP templates have been made widely available by a number of cancer organizations. For example, the Journey Forward SCP template, (i.e. Survivorship Care Plan Builder), is a free online tool developed by a collaboration of cancer organizations that allows oncology providers to create personalized electronic SCPs for their patients that can be printed, emailed, edited, and stored electronically. The American Society of Clinical Oncology (ASCO), meanwhile, has developed disease-specific SCP templates in PDF format available for oncology providers to download, print, and complete for their patients. In addition to these widely available templates, health systems can also internally develop their own SCP templates for use with their patients.

All study authors requested SCPs via phone or email from key hospital oncology contacts identified from hospital websites or from personal and professional contacts, inquiring whether SCPs for breast or colorectal survivors were used at the institution, and if so, whether we could obtain a blank or deidentified copy to review in our study. SCPs translated into languages other than English were also requested and obtained when available. We informed each institutional contact that any SCP information shared with us would not be linked to their specific institution in our analysis.

Analytic strategy

We evaluated the content of SCPs to 1) determine the extent to which they captured the elements recommended by the IOM and 2) assess their overall communication appropriateness for adult patients, including readability (reading grade level) and cultural appropriateness.

IOM Concordance

The IOM recommends that SCPs contain 1) a record of all care received (treatment summary), and 2) a follow-up care plan incorporating available evidence-based standards of care. Specifically, the treatment summary includes details of the cancer diagnosis (diagnosis date, type of cancer, location, stage, histology); names and contact information for treating providers; and details of specific treatments administered (chemotherapy, radiation, surgery). The follow-up plan portion, meanwhile, contains specific recommendations for ongoing care, including schedule of visits with oncology specialist and primary care physician; surveillance testing for recurrence, description of long-term and late effects; health promotion strategies; and cancer-related resources [7]. Prior studies of SCPs have yielded tools for evaluating SCP concordance with IOM recommendations [8–10]. After reviewing these multiple approaches, we adapted standardized methods from a study that created an evaluation tool for breast and colorectal cancer-specific SCPs by operationalizing the 18 sections of the IOM framework of recommended SCP content into a checklist of identifiable items [8]. We analyzed collected SCPs by coding whether they contained each component on the checklist, and then generating an overall percentage of included elements. Study author HL independently coded each SCP for IOM concordance, and study author US reviewed all coding decisions. Discrepancies were resolved by discussion with the study team.

Communication appropriateness

Next, we conducted an assessment of the overall communication appropriateness of the SCPs to understand whether patients from diverse racial, ethnic, and socioeconomic backgrounds are likely to understand, accept, and use the plans. To assess communication appropriateness, we used a modified version of the Suitability Assessment of Materials (SAM) instrument [12] (Table 1). Designed to be a rigorous and quantified evaluation of patient education materials and validated with 172 health care providers from diverse cultures, the SAM instrument assesses patient suitability across 22 key factors, including content, literacy demand, graphics, layout and typography, learning stimulation, motivation, and cultural appropriateness. For each element assessed, the SAM framework provides a numerical score that may fall into one of three categories: superior (2), adequate (1), or not

suitable (0). Overall suitability of a document is assessed by adding the ratings of each factor and dividing by the total possible score to generate a percent score, which is then grouped into ratings as follows: superior (70–100%); adequate (40–69%); and not suitable (0–39%).

To assess literacy demand, the SAM framework employs the Fry readability formula. The Fry formula generates a grade-level rating of running text by averaging the number of sentences and syllables per 100-words. Grade-level ratings range from grade 1 through grade 17. A higher grade-level rating indicates a greater level of difficulty to read and comprehend the text. The Fry formula is a widely accepted tool among health care professionals for assessing the readability of written patient education materials [13].

In addition, the SAM framework measures cultural appropriateness by assessing how well central concepts and ideas of a document appear to be culturally similar to the logic, language, and experience of the intended patient population, and whether cultural images and examples are presented in realistic and positive ways [12]. Based on the instructions provided in the SAM framework, cultural appropriateness is to be scored based on the intended cultural audience of the document being assessed [12]. Because it was often not possible for the study team to determine the intended cultural audience of each SCP in our sample, we uniformly scored the plans with the assumption that the target audience of all collected plans was a racially diverse patient population, as we believe that every cancer care provider should have the tools available to adequately treat a diverse population. As such, the study team scored all plans that appeared to target only an English-speaking, Caucasian patient population as "adequate," while plans received a "superior" rating if they made an attempt to provide tailoring for a more racially and ethnically diverse audience.

The SAM instrument has previously been used to assess suitability of a variety of patient education materials, including prostate cancer education materials [14], colorectal cancer webpages [15], and written education materials for stroke patients [16]. Study author MB scored each SCP using a modified version of the SAM framework, and study author HL reviewed all scoring decisions. Discrepancies were resolved by discussion with the study team.

Results

SCP sample

Fifty-three total health systems responded to our inquiry for SCPs. Of the 53, 18 (34%) reported using either the ASCO or Journey Forward SCP templates or modified versions of these templates. The remaining health systems either developed SCPs internally (53%), or reported that SCPs were not currently in use at their institution (13%). In an effort to analyze equal numbers of breast and colorectal cancer plans in use in different hospital settings and distributed evenly across geographic regions, we analyzed a subset of the SCPs we received for the present analysis (n=16). The plans in our sample of 16 include seven breast cancer plans, seven colorectal cancer plans, and two generic cancer plans. These 16 plans were collected from four community hospitals, three safety-net hospitals, four academic medical centers, and two IDSs across the Midwestern and Western regions of the U.S. Of the 16 plans, 14 are internally developed plans, one is a Journey Forward SCP template, and

one is an ASCO SCP template. Analyzing this sample allowed us to assess how internally developed SCPs compare across health systems and in relation to the publically available templates.

IOM concordance

None of the SCPs in our sample incorporated all of the elements recommended by the IOM. Plans ranged from incorporating 31% to 77% of the IOM's recommendations for content, with the majority of plans (n=11) incorporating less than 60% of recommended content. Grouped by hospital type, the plans ranged from including an average of 48% of the IOM recommended components (safety-net plans) to 60% of the recommended components (academic medical center plans). IDS plans included an average of 51% of the components, and community hospital plans included an average of 56% of the components (Table 2). Within the treatment summary portion of the plans, key recommended components that nearly all plans in our sample incorporated included: a description of tumor characteristics (i.e. site, stage, grade), whether chemotherapy was administered and the name of the drug, whether surgery was performed and what procedure was used, and the name of at least one cancer care provider who treated them. Plans varied in their inclusion of information regarding radiation and hormone therapy (breast cancer plans only). All of the plans, meanwhile, failed to include whether psychosocial, nutritional, or other supportive services were provided during treatment. In the follow-up care plan section of the plans, plans varied in their inclusion of recommendations for screening for other cancers and cancer recurrence, the timing of future cancer screening, and providing contact information for a continuing cancer care key contact. Nearly every plan, however, mentioned the potential need for future psychosocial support, recommendations for healthy behaviors (i.e. diet, exercise, smoking cessation), and cancer-related resources (i.e. names or websites of cancer support organizations).

Communication appropriateness

None of the SCPs received a "superior" overall suitability rating. By hospital type, plans collected from academic hospitals had the highest mean SAM rating of 47%, corresponding to an "adequate" SAM rating. Plans from community hospitals, safety-net health systems, and IDSs had mean SAM ratings of 39%, 38%, and 29% respectively, each corresponding to a "not suitable" rating. Reading grade levels of all plans ranged from grade 9 (safety-net health system plan), to grade 18 (IDS plan), with a mean of grade 14. By hospital type, plans from safety-net health systems had the lowest mean reading grade level of 12, while plans from IDSs had the highest mean reading grade level of 16. Mean reading grade levels from community hospitals and academic medical centers were both grade 14. Finally, only one plan in our sample received a "superior" rating for cultural appropriateness. This was an internally developed plan from a safety-net health system that was written in three languages (English, Spanish, and Chinese). The remaining plans in our sample failed to demonstrate tailoring for diverse racial/ethnic groups and received an "adequate" score for presenting information most appropriate for English-speaking, Caucasian patient populations (Table 3).

Discussion and Conclusion

Discussion

Our analysis of a sample of SCPs in use in diverse health care settings in the U.S. demonstrates that there is significant variability in the content and communication appropriateness of SCPs. First, consistent with prior studies analyzing the content of SCPs in relation to the IOM recommendations [8, 17], our analysis reveals that SCPs in our sample fail to consistently meet the IOM criteria for SCPs, with many plans including less than half of the recommended elements. The absence of many recommended elements in most SCPs may represent a deficiency in the plans, or perhaps suggests that providers perceive certain data elements as either too difficult, or not important enough, to routinely include in SCPs. Omission of information about possible recurrence, future cancer screening, and cancer care key contact raises particular concerns about the utility of SCPs for addressing possible care gaps in future cancer-related health care.

Recognizing the failure of many SCPs in use across the country to include all of the IOM recommendations, ASCO released a clinical expert statement on cancer survivorship care planning in 2014 that put forward what they deemed to be the minimum essential elements needed in an SCP [18]. In particular, the expert panel recommended that many of the specific elements of the IOM recommendations, such as inclusion of a comprehensive list of possible symptoms of cancer recurrence, a description of late and long-term effects of treatment, and a list of specific lifestyle or health promotion elements, be discarded in favor of brief general statements about these issues. In this way, the ASCO statement represents an important effort to consolidate the initial IOM recommendations into simple, essential components to more reliably serve cancer survivors, their families, and PCPs. Our findings reinforce the probable need to move toward a more consolidated framework, supported by consensus, as to what elements can be feasibly included in SCPs to meet cancer survivors' information needs. Future research in which consolidated SCP frameworks are piloted with diverse patient populations will be crucial in assessing whether these consolidated SCPs are meeting survivors' varied needs.

Next, our communication appropriateness assessment highlights that SCPs used in diverse settings are not written at an appropriate grade level so as to be easily understood by patients. The American Medical Association (AMA) recommends that written health education materials should not exceed a sixth-grade reading level [19]. What is more, the AMA suggests avoiding technical words or jargon in written health materials, and defining medical terminology when introduced. Previous research has found that cancer survivors prefer survivorship care information to be presented to them in easy-to-understand, lay language [20–22]. Our findings, however, demonstrate that all SCPs in our sample are written above a high school reading level, with many plans written above a grade 12 level. To address disparities in cancer care, it is critical that written health materials be easily understood by vulnerable, underserved patient populations. Our findings clearly indicate that SCPs currently in use are not meeting the communication needs of patients with limited health literacy and low English proficiency. SCPs should be adapted according to existing best-practices for health education materials across literacy levels, co-developed

with diverse, low-literacy patient populations, and tested iteratively to ensure that they are easily understood.

In addition, our results reveal that SCPs suffer from a lack of tailoring to diverse populations. Previous research has shown that culturally diverse patients have specific needs and preferences when it comes to SCPs. For example, one study found that Chinese American breast cancer survivors have a strong desire for information on reputable traditional Chinese medicine and for SCPs to be offered in both English and Chinese [21], while another study found that African American breast cancer survivors prefer SCPs to contain more information on diet and nutrition in relation to foods prevalent in the African American community, as well as information on specific comorbidities that are most prevalent among African Americans, including high blood pressure, diabetes, and weight control issues [23]. Our findings, however, reveal that SCPs in use in a variety of hospital settings fail to demonstrate tailoring for diverse racial/ethnic groups. Availability in multiple languages, and representation of culturally sensitive images and information for populations besides White patients was virtually nonexistent in our sample of SCPs. This significant lack of tailoring among SCPs in our sample may contribute to the creation or worsening of health and health care disparities. Co-designing SCPs with diverse patient populations is crucial to ensure that these documents are meeting the needs and preferences of all cancer survivors and may help to address racial and ethnic disparities in cancer knowledge among diverse survivor populations [24].

Across health care settings, plans from academic medical centers included, on average, the most recommended IOM components and had the highest mean SAM score compared to plans from community and safety-net hospitals and IDSs. This finding suggests that a greater availability of resources and staff time in a health care setting affords a greater ability to develop comprehensive and understandable SCPs. Nevertheless, even plans from academic medical centers fell short of incorporating all of the recommended IOM components and tailoring plans to diverse populations at an appropriate reading grade level. Given that existing national SCP templates (e.g., ASCO or Journey Forward) are widely used among health care organizations, the development by national organizations of SCPs that are tailored for other cultures and languages and written at a low literacy level would be a valuable investment to support patients seen in facilities without adequate resources or personnel to internally develop such SCPs.

Our study has several key limitations. First, our sample represents 16 SCPs collected from two distinct geographic regions of the U.S., which circumscribes the generalizability of our findings. Second, only one study author coded the SCPs for concordance with IOM recommendations, and only one study author coded the SCPs for overall communication appropriateness. Next, our assessment of cultural appropriateness may not have adequately captured the complexities of the concept in relation to the SCPs. Future studies of SCPs could employ different developed measures of cultural sensitivity to more thoroughly assess the extent of cultural tailoring of SCPs. Finally, future studies could enrich the findings presented in this paper through in-depth qualitative interviews with frontline clinicians and staff from a variety of health care settings about SCP development and implementation.

Conclusion

Our findings demonstrate that there is significant variation in the format and content of SCPs currently in use across a wide breadth of health care settings, including academic, community, safety-net, and IDS hospitals. Most plans fail to meet the IOM criteria for SCPs and are not written at an appropriate reading grade level nor tailored for underserved and/or minority patient populations.

Implications for Cancer Survivors

This study's results suggest that there is an ongoing need to develop more patient-centered, comprehensible, efficient SCPs to better meet the needs of cancer survivors. More effectively communicating critical health information to cancer survivors from diverse backgrounds through a re-envisioning of the content and format of SCPs with diverse patient populations will be necessary to promote equitable patient communication and survivorship care.

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References

- [1]. Miller KD, Siegel RL, Lin CC, Mariotto AB, Kramer JL, Rowland JH, Stein KD, Alteri R, Jemal A. 2016. Cancer treatment and survivorship statistics. CA: A cancer journal for clinicians 66(4):271–289. [PubMed: 27253694]
- [2]. Siegel RL, Miller KD, Jemal A. 2019. Cancer statistics. CA: A cancer journal for clinicians 69:7–34. [PubMed: 30620402]
- [3]. Parry C, Kent EE, Mariotto AB, Alfano CM, Rowland JH. 2011. Cancer survivors: A booming population. Cancer Epidemiology and Prevention Biomarkers 20(10):1996–2005.
- [4]. Pisu M, Kenzik KM, Oster RA, Drentea P, Ashing KT, Fouad M, Martin MY. 2015. Economic hardship of minority and non-minority cancer survivors 1 year after diagnosis: Another long-term effect of cancer?. Cancer 121(8):1257–1264. [PubMed: 25564986]
- [5]. Aziz NM, Rowland JH. 2002. Cancer survivorship research among ethnic minority and medically underserved groups. Oncology Nursing Forum 29(5):789–806. [PubMed: 12058154]
- [6]. Smedley BD, Haynes MA. 1991. The unequal burden of cancer: An assessment of NIH research and programs for ethnic minorities and the medically underserved. Washington DC: The National Academies Press.
- [7]. Council NR. 1995. From cancer patient to cancer survivor: Lost in transition. Washington DC: The National Academies Press.
- [8]. Salz T, Oeffinger KC, McCabe MS, Layne TM, Bach PB. 2012. Survivorship care plans in research and practice. A: A Cancer Journal for Clinicians 62(2):101–117.
- [9]. Stricker CT, Jacobs LA, Risendal B, Jones A, Panzer S, Ganz PA, Syrjala KL, McCabe MS, Baker KS, Miller K. 2011. Survivorship care planning after the institute of medicine recommendations: How are we faring?. Journal of Cancer Survivorship 5(4):358–370. [PubMed: 21968543]
- [10]. Palmer SC, Jacobs LA, DeMichele A, Risendal B, Jones AF, Stricker CT. 2014. Metrics to evaluate treatment summaries and survivorship care plans: A scorecard. Supportive Care in Cancer 22(6):1475–1483. [PubMed: 24414997]
- [11]. Desmond RA, Jackson BE, Waterbor JW. 2017. Disparities in cancer survivorship indicators in the Deep South based on BRFSS data: Recommendations for survivorship care plans. Southern Medical Journal 110(3):181–187. [PubMed: 28257542]

[12]. Doak CC, Doak LG, Root JH. 1985. Teaching patients with low literacy skills. Pennsylvania: Lippincott Williams and Wilkins.

- [13]. Ley P, Florio T. 1996. The use of readability formulas in health care. Psychology, Health & Medicine 1(1):7–28.
- [14]. Weintraub D, Maliski SL, Fink A, Choe S, Litwin MS. 2004. Suitability of prostate cancer education materials: Applying a standardized assessment tool to currently available materials. Patient Education and Counseling 55(2):275–280. [PubMed: 15530765]
- [15]. Kaphingst KA, Zanfini CJ, Emmons KM. 2006. Accessibility of web sites containing colorectal cancer information to adults with limited literacy (United States). Cancer Causes & Control 17(2):147–151. [PubMed: 16425092]
- [16]. Hoffmann T, McKenna K. 2006. Analysis of stroke patients' and carers' reading ability and the content and design of written materials: Recommendations for improving written stroke information. Patient Education and Counseling 60(3):286–293. [PubMed: 16098708]
- [17]. Daudt H, Van Mossel C, Dennis D, Leitz L, Watson H, Tanliao J. 2014. Survivorship care plans: A work in progress. Current Oncology 21(3):e466–e479. [PubMed: 24940107]
- [18]. Mayer DK, Nekhlyudov L, Snyder CF, Merrill JK, Wollins DS, Shulman LN. 2014. American Society of Clinical Oncology clinical expert statement on cancer survivorship care planning. Journal of Oncology Practice 10(6):345–351. [PubMed: 25316025]
- [19]. Weiss BD. 2007. Health literacy and patient safety: Help patients understand. Manual for clinicians. American Medical Association Foundation.
- [20]. Burke NJ, Napoles TM, Banks PJ, Orenstein FS, Luce JA, Joseph G. 2016. Survivorship care plan information needs: Perspectives of safety-net breast cancer patients. PloS One 11(12):1–15.
- [21]. Wen K-Y, Hu A, Ma GX, Fang CY, Daly MB. 2014. Information and communication needs of Chinese American breast cancer patients: Perspectives on survivorship care planning. The Journal of Community and Supportive Oncology 12(12):439. [PubMed: 25811036]
- [22]. Hewitt ME, Bamundo A, Day R, Harvey C. 2007. Perspectives on post-treatment cancer care: Qualitative research with survivors, nurses, and physicians. Journal of Clinical Oncology 25(16):2270–2273. [PubMed: 17538172]
- [23]. Ashing-Giwa K, Tapp C, Brown S, Fulcher G, Smith J, Mitchell E, Santifer RH, McDowell K, Martin V, Betts-Turner B. 2013. Are survivorship care plans responsive to African-American breast cancer survivors?: Voices of survivors and advocates. Journal of Cancer Survivorship 7(3):283–291. [PubMed: 23471728]
- [24]. Freedman RA, Kouri EM, West DW, Keating NL. 2015. Racial/ethnic disparities in knowledge about one's breast cancer characteristics. Cancer 121(5):724–732. [PubMed: 25624186]

Table 1.Modified Suitability Assessment of Materials (SAM) evaluation tool for assessing communication appropriateness

Criteria	Definition	Example from SCPs			
Content					
Purpose is evident	Purpose is explicitly stated in title, or cover illustration, or introduction	"This Cancer Care Plan will facilitate cancer care following active treatment"			
Content about behaviors	Thrust of information is application of knowledge/skills aimed at desired behavior	"Make half your plate fruits and vegetables"			
Summary or review included	Summary is included and retells key messages in different words/examples	"This summary is a brief record of major aspects of your cancer treatment"			
Literacy Demand					
Reading grade level	Calculated with Fry formula (see example). Ideal is 6 th grade level or lower	"Rest, fatigue, and exercise: Extreme tiredness, called fatigue, is very common in people treated for cancer. This is not a normal tiredness, but a "bone-weary" exhaustion that doesn't" 25-word sample portion (running text): 1.8 sentences, 41 syllables 1.8*4 = 7.2 sentences, 41*4			
Vocabulary uses common words	Common, explicit words are used (i.e. doctor instead of physician)	= 164 syllables Sample portion: 11+ grade level			
Context is given first	Consistently provides context before presenting new information				
Learning aids via "road signs"	Nearly all topics preceded by advance organizer				
Graphics					
Type of graphics	Illustrations are simple, adult-appropriate, and likely to be familiar to viewer	TNM Staging for Breast Cancer			
Relevance of illustrations	Illustrations present key messages so the reader/viewer can grasp key ideas	N CATEGORY Internal mammary node Axillary node Metastases in:			
Lists, tables, etc. explained	Explanatory captions with all or nearly all illustrations and graphics	Bone Lung Liver T CATEGORY Breast cancer primary			
Layout and typogr	aphy				
Typography	Layout is not distracting	Your wellness checklist: ✓ Healthy eating ✓ Smoking cessation			
Layout factors	Text allows for easy comprehension				
Subheadings used	Subheadings used for lists	✓ Body weight management			

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Criteria Definition Example from SCPs ✓ Limit alcohol consumption Learning stimulation, motivation Behaviors Instruction models modeled and specific behaviors or specific skills "If you haven't exercised in a few years, you will have to start slowly - maybe just by taking Motivation Complex topics are subdivided into small selfefficacy short walks. Ideally working up to 30 minutes of moderate aerobic activity per day, 5 days per week is recommended... parts Cultural appropriateness Principal Oncologist Provider: *Oncologo principal* 主要腫瘤醫師提供者 Match in Central concepts/ideas logic, language, and experience of material appear to be culturally similar to (LLE) LLE of target culture Cultural Images and examples present the culture in image and examples positive ways

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Table 2. Concordance with IOM recommendations by hospital type

IOM Components	Safety net plans (n=4) N (%)	Community plans (n=4) N (%)	Academic plans (n=4) N (%)	IDS plans (n=4) N (%)
Date of diagnosis	4 (100)	3 (75)	4 (100)	3 (75)
Tumor characteristics	4 (100)	4 (100)	4 (100)	4 (100)
Chemotherapy				
Whether used	4 (100)	4 (100)	4 (100)	4 (100)
Name of drug	4 (100)	4 (100)	4 (100)	4 (100)
Dose	1 (25)	1 (25)	3 (75)	0 (0)
Date started	1 (25)	1 (25)	4 (100)	4 (100)
Date stopped	1 (25)	4 (100)	4 (100)	2 (50)
Treatment response	2 (50)	1 (25)	1 (25)	3 (75)
Toxicities	2 (50)	3 (75)	1 (25)	1 (25)
Radiation				
Whether used	3 (75)	3 (75)	4 (100)	3 (75)
Dose	0 (0)	1 (25)	2 (50)	1 (25)
Location	2 (50)	3 (75)	3 (75)	1 (25)
Date started	0 (0)	0 (0)	3 (75)	1 (25)
Date stopped	2 (50)	3 (75)	3 (75)	0 (0)
Treatment response	0 (0)	0 (0)	1 (25)	2 (50)
Toxicities	0 (0)	2 (50)	1 (25)	1 (25)
Surgery				
Whether used	3 (75)	4 (100)	4 (100)	4 (100)
Procedure	3 (75)	4 (100)	4 (100)	4 (100)
Date	2 (50)	4 (100)	3 (75)	2 (50)
Complications	0 (0)	0 (0)	0 (0)	2 (50)
Hormone therapy (breast plans only)				
Whether used	2 (100)	1 (50)	1 (50)	2 (100)
Date started	0 (0)	0 (0)	1 (50)	1 (50)
Date stopped	1 (50)	1 (50)	1 (50)	0 (0)
Treatment response	0 (0)	0 (0)	1 (50)	1 (50)
Toxicities	0 (0)	0 (0)	1 (50)	1 (50)
Clinical trials				1
Whether participated	1 (25)	2 (50)	2 (50)	3 (75)
Date	0 (0)	0 (0)	0 (0)	2 (50)
Number and other identifying info	0 (0)	0 (0)	1 (25)	2 (50)
Psychosocial services provided	0 (0)	0 (0)	0 (0)	0 (0)
Nutritional services provided	0 (0)	0 (0)	0 (0)	0 (0)
Other supportive services provided	0 (0)	0 (0)	0 (0)	0 (0)

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IOM Components	Safety net plans (n=4) N (%)	Community plans (n=4) N (%)	Academic plans (n=4) N (%)	IDS plans (n=4) N (%)
Name(s) of cancer care provider(s)	4 (100)	4 (100)	4 (100)	4 (100)
Contact information for cancer care provider(s)	1 (25)	3 (75)	2 (50)	0 (0)
Continuing cancer care key contact	2 (67)	2 (50)	2 (50)	1 (25)
Contact information for continuing primary care	3 (75)	4 (100)	3 (75)	1 (25)
Information on when to visit primary care provider	3 (75)	3 (75)	3 (75)	3 (75)
Likely course of recovery from treatment toxicities	2 (50)	1 (25)	1 (25)	0 (0)
Recommendation for 2 nd primary cancer/ recurrence surveillance	4 (100)	3 (75)	4 (100)	4 (100)
Information regarding who provides 2 nd primary surveillance	4 (100)	3 (75)	2 (50)	2 (50)
Information regarding timing of 2 nd primary surveillance	4 (100)	3 (75)	4 (100)	4 (100)
Recommendation for screening for other cancers	2 (50)	2 (50)	3 (75)	4 (100)
Information regarding who provides cancer screening	2 (50)	2 (50)	3 (75)	4 (100)
Information regarding timing of cancer screening	0 (0)	1 (25)	2 (50)	0 (0)
Recommendation for other tests	2 (50)	2 (50)	3 (75)	1 (25)
Information regarding who provides other tests	2 (50)	2 (50)	2 (50)	0 (0)
Information on timing of other tests	2 (50)	2 (50)	3 (75)	0 (0)
Late and long-term effects of treatments	2 (50)	4 (100)	2 (50)	2 (50)
Possible signs of recurrence and second tumors	1 (25)	2 (50)	1 (25)	2 (50)
Marital/partner, sexual functioning, work, parenting effects	3 (75)	3 (75)	2 (50)	3 (75)
Potential need for future psychosocial support	3 (75)	4 (100)	3 (75)	4 (100)
Insurance, employment, legal aid, financial assistance information	3 (75)	2 (50)	2 (50)	3 (75)
Recommendations for healthy behaviors	3 (75)	4 (100)	4 (100)	4 (100)
Recommendations for relatives' screening if at increased risk	2 (50)	0 (0)	0 (0)	0 (0)
Genetic counseling information to identify high risk people	2 (50)	3 (75)	4 (100)	3 (75)
Information on chemoprevention	0 (0)	2 (50)	0 (0)	1 (25)
Referrals to other providers	4 (100)	2 (50)	1 (25)	0 (0)
Cancer-related resources	3 (75)	4 (100)	4 (100)	4 (100)
Mean % of IOM components present	48%	56%	60%	51%

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Table 3.Overall communication appropriateness of SCPs based on the Suitability Assessment of Materials (SAM) evaluation tool by hospital type

Hospital type	SCP	Reading grade level	Cultural appropriateness	Overall SAM score* (%)
	Plan 1	13	Superior	44
	Plan 2	14	Adequate	41
Safety net	Plan 3	9	Adequate	41
	Plan 4	10	Adequate	26
		Mean: 12		Mean: 38
Community	Plan 5	17	Adequate	38
	Plan 6	11	Adequate	59
	Plan 7	12	Adequate	29
	Plan 8	14	Adequate	29
		Mean: 14		Mean: 39
Academic	Plan 9	10	Adequate	62
	Plan 10	17	Adequate	21
	Plan 11	12	Adequate	53
	Plan 12	17	Adequate	50
		Mean: 14		Mean: 47
IDS	Plan 13	10	Adequate	35
	Plan 14	18	Adequate	32
	Plan 15	17	Adequate	24
	Plan 16	17	Adequate	24
		Mean: 16		Mean: 29

^{*}Overall suitability using SAM: 70–100% superior; 40–69% adequate, 0–39% not suitable