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Title: *Health Literacy: An Analysis of Childhood Cancer Family Guidebooks*

The accompanying research report is submitted to the **University of Wisconsin-Stout, Graduate School** in partial completion of the requirements for the

Graduate Degree/ Major: MS Technical and Professional Communication

Research Advisor: Dr. Kate Roberts Edenborg

Submission Term/Year: Spring 2024

Number of Pages: 33

Style Manual Used: American Psychological Association, 7th edition

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Wallace, Lynn R. *Health Literacy: An Analysis of Childhood Cancer Family Guidebooks*

Abstract

This study investigates the effectiveness of family medical handbooks distributed during childhood cancer diagnosis and treatment in promoting personal health literacy. After conducting a literature review on literacy, health literacy, and clear communication, an analysis was completed to determine how closely three childhood cancer advocacy organizations used health literacy concepts in developing their handbooks. The three handbooks analyzed are from the American Childhood Cancer Organization, Children’s Oncology Group, and the National Pediatric Cancer Foundation. Utilizing the Center of Disease Control’s (CDC) “Simply Put: A guide for creating easy-to-understand materials,” the three handbooks were analyzed to see if they met the benchmarks in four categories. This analysis assessed message content, text appearance, visuals, and layout and design.

Acknowledgments

I want to thank Dr. Kate Roberts Edenborg, my advisor, and Dr. Gregory Schneider-Bateman, the MSTPC program director, for their invaluable guidance, mentorship, and patience throughout my graduate education.

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Chapter I: Introduction

It is not uncommon for families to feel inundated by the amount of information they receive from medical professionals when a new or unexpected medical problem arises. The initial visit, diagnosis, and treatment process can be overwhelming. Doctors, nurses, and other healthcare providers, such as child-life specialists, provide information about the condition, possible causes, treatment options, and potential outcomes. Receiving information can be particularly challenging for families with complex conditions or limited experience navigating the healthcare system (Polakova et al., 2024). Medical professionals should communicate clearly and effectively with patients and their families, answering questions, providing reassurance, and offering support throughout the treatment process (Sisk et al., 2021). When dealing with medical professionals, personal health literacy becomes crucial, especially in cases of childhood cancer diagnosis and treatment.

Personal health literacy refers to the ability to find and utilize information to make informed decisions about health for yourself and others (Centers for Disease Control, 2021). The researcher found that personal health literacy was an important part of the diagnosis and treatment of childhood cancer in her family. It helped her family make important decisions about her minor child and established a valuable connection to the healthcare providers they interacted with such as the oncologist, nurses, and child-life specialists. Health literacy helped my family receive complex medical guidance and communicate our concerns to medical staff. Health literacy enhanced our communication and played a large role in the diagnosis and treatment of childhood cancer in my family.

Statement of the Problem

Working through a childhood cancer diagnosis and treatment may be challenging due to the complexities of the situation. Communicating complex medical information to families in stressful situations can be especially challenging if the family has little personal health literacy experience or literacy concerns in general.

Purpose of the Study

The focus of this study is to review family medical handbooks distributed during childhood cancer diagnosis and treatment to determine how close they follow personal health literacy principals. This study examines three handbooks developed by childhood cancer advocacy organizations. This study aims to determine how close the handbooks can help families understand medical terminology, treatments, and provide support to families in need.

Assumptions of the Study

Regarding this study, the following assumptions exist.

1. The three family handbooks analyzed are assumed to be accessible to the public online, in hard copy format at the clinic or hospital, or mailed to the family by the organization by request or available to purchase on the organization's website.
2. The three family handbooks analyzed are assumed to be recommended by medical professionals such as nurses, doctors, or child-life specialists during childhood cancer diagnosis and treatment.
3. The three family handbooks analyzed are assumed to be used as a reference by the families of childhood cancer patients during the diagnosis and treatment of childhood cancer.

4. The three family handbooks analyzed are assumed to be available in a language the reader understands.
5. The readers of the three handbooks are assumed to believe the content of the handbooks to be accurate.

Definition of Terms

The following terms will help explain key concepts related to this study.

Cancer

A term for diseases in which abnormal cells divide without control and can invade nearby tissues. Cancer cells can also spread to other parts of the body through the blood and lymph systems (National Cancer Institute, n.d.-a).

Childhood cancer

A term used to describe cancers that occur between birth and 14 years of age. Childhood cancers are very rare and may differ from adult cancers in the way they grow and spread, how they are treated, and how they respond to treatment—also called pediatric cancer (National Cancer Institute, n.d.-b).

Child-life specialist

A healthcare professional who is trained in the emotional and developmental needs of children. A child-life specialist helps children, and their families understand medical issues and gives psychological and emotional support (National Cancer Institute, n.d.-c).

Diagnosis

The process of identifying a disease, condition, or injury from its signs and symptoms. A health history, physical exam, and tests, such as blood tests, imaging tests, and biopsies, may be used to help make a diagnosis (National Cancer Institute, n.d.-d).

Effectiveness

How influential a childhood cancer family handbook is in helping a family diagnosed with childhood cancer understand and use medical knowledge.

Literacy

Understanding, evaluating, using, and engaging with written text to participate in society, achieve one's goals, and develop one's knowledge and potential National Center for Education Statistics. (n.d.).

Nurse

A health professional trained to care for people who are ill or disabled (National Cancer Institute, n.d.-e).

Oncologist

A doctor who has special training in diagnosing and treating cancer. Some oncologists specialize in a particular type of cancer treatment. For example, a radiation oncologist specializes in treating cancer with radiation (National Cancer Institute, n.d.-f).

Oncology

A branch of medicine that specializes in the diagnosis and treatment of cancer. It includes medical oncology (the use of chemotherapy, hormone therapy, and other drugs to treat cancer), radiation oncology (the use of radiation therapy to treat cancer), and surgical oncology (the use of surgery and other procedures to treat cancer) (National Cancer Institute, n.d.-g).

Organizational health literacy

The degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others (Centers for Disease Control, 2021).

Personal health literacy

The degree to which individuals can find, understand, and use information and services to inform health-related decisions and actions for themselves and others (Centers for Disease Control, 2021).

Social worker

A professional trained to talk with people and their families about emotional or physical needs and to find them support services (Centers for Disease Control, 2021).

Treatment plan

A detailed plan with information about a patient's disease, the goal of treatment, the treatment options for the disease and possible side effects, and the expected length of treatment.

A treatment plan may also include information about how much the treatment will cost and about regular follow-up care after treatment ends (National Cancer Institute, n.d.-h).

Limitations of the Study

The limitations of this study include:

1. There may be other organizations that have developed guidebooks not analyzed during this study.
2. There may be other medical companies that have developed guidebooks not analyzed during this study.
3. No human subjects research was completed to provide the opinions of other families or patients that may have health literacy concerns during childhood cancer.
4. It is unknown what processes or guidance the three organizations used to create their handbooks.
5. The handbooks can become outdated as best medical practices are updated.

6. This study did not analyze the concept of cultural or religious differences in medical care.

Chapter II: Literature Review

This literature review looks into the topics of literacy and health literacy. It was also an opportunity for the researcher to review the findings of a previous study of communication during childhood cancer at three prominent times: treatment, survivorship, or bereavement. It also looks at health literacy organization history. There are some organizations that have similar missions to empower families and patients to navigate health and literacy issues. This literature review aspires to identify ways these organizations can help empower patients and their families during a childhood cancer diagnosis.

Literacy

Literacy, as defined by the US Department of Education, is understanding, evaluating, using, and engaging with written text to participate in society, achieve one's goals, and develop one's knowledge and potential (National Center for Education Statistics, n.d.). Competence in literacy allows families in medical situations to effectively communicate during doctor appointments and treatment. One specific type of literacy is health literacy, which is the ability to gather, process, and understand health information (Centers for Disease Control and Prevention, n.d.).

Health Literacy

The definition of health literacy was recently updated in 2020 by the Centers for Disease Control. Their new definition is part of the US Government's Healthy People in 2030 initiative. The Centers for Disease Control defines health literacy as two separate definitions. The definition of health literacy is now divided into personal health literacy and organizational health literacy. According to the Centers for Disease Control in 2020, personal health literacy is "the degree to which individuals have the ability to find, understand, and use information and services

to inform health-related decisions and actions for themselves and others.” The Centers for Disease Control defines organizational health literacy as “the degree in which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.”

The CDC updating their literacy definitions show that individuals have responsibility for their own decisions. The updated definitions are identifying the need for individuals to understand and apply literacy and health literacy information. These definitions are ideal because it puts the power into the individuals’ hands to apply the information and find better outcomes.

Health Literacy Organizations

The CDC is a prominent organization that provides health literacy information to the public (Centers for Disease Control and Prevention, n,d.). As part of the US Government's Department of Health and Human Services, it can handle both proactive and reactive health education. Organizations and government agencies are set up to help families navigate the challenges with literacy and health literacy through their established missions.

Previous Childhood Cancer Communication Studies

The researcher has identified a qualitative study conducted by Bryan A. Sisk, Annie Friedrich, Lindsay J. Blazin, Justin N. Baker, Jennifer W. Mack, and James DuBois in 2021. The researchers are associated with the Division of Hematology/Oncology at the Washington School of Medicine, St. Jude Children's Research Hospital, the Dana-Farber Cancer Institute, Boston’s Children's Hospital, and the Washington University School of Medicine (Sisk et al., 2021).

The researchers interviewed 78 parents of children with cancer at one of three points in the childhood cancer journey: treatment, survivorship, or bereavement. Their study is relevant to this study because it studies communication within pediatric oncology. Their secondary analysis

provides insight into other parents' experiences with communication within pediatric oncology.

Here are their findings:

The researchers identified six functions of communication between children and clinicians, from the parental perspective: building relationships, promoting patient engagement, addressing emotions, exchanging information, managing uncertainty, and fostering hope. These functions were all identified by parents of younger (12 years and younger) and older (13 years and older) children (Sisk et al., p. 3, 2021).

Building Relationships

In 71 out of 80 interviews they conducted, consensus showed that fostering relationships between clinicians and patients is critical in enhancing rapport and facilitating effective clinical care (Sisk et al., 2021). This emphasis on building connections not only strengthens rapport but also plays a role in easing communication, particularly in moments of stress. According to the researchers findings by prioritizing the cultivation of caring relationships, clinicians can create an environment conducive to trust, understanding, and ultimately, more effective patient care.

Promoting Patient Engagement

Promoting engagement by engaging in direct interaction with the patient was identified in 59 out of 80 interviews, showing a high level of interest in this function (Sisk et al., 2021). When children actively participate, it fosters effective communication because they could be intrigued by the processes. This interest drives their engagement, making direct interaction with them a valuable aspect of communication strategies.

Addressing Emotions

Addressing emotions and respecting boundaries when communicating with patients was identified in 58 out of 80 transcripts (Sisk et al., 2021). Healthcare professionals need to be

aware that pushing too hard or discussing sensitive topics can harm patient trust and lead to a breakdown in communication between patients and medical staff.

Exchanging Information

In 53 out of 80 transcripts, exchanging information with the patient to inform the child of what is going on was identified as an essential function. This allows clinicians to be honest and present information in a way that the patient can understand. This function was particularly important (Sisk et al., 2021). According to the researcher's findings, by actively involving patients in their care and decision-making processes, medical staff can enhance patient trust and help adherence to treatment plans.

Managing Uncertainty

Managing uncertainty where clinicians foster positive interactions to maintain hope during communications was identified in only 31 out of 80 transcripts (Sisk et al., 2021). According to the researcher's findings, clinicians must find a delicate balance between providing information and maintaining hope, especially when dealing with pediatric patients. While some clinicians may avoid challenging discussions during diagnosis, treatment, and survivorship to shield young patients from doubt and worry, it can be essential to address uncertainties openly and honestly. This approach can help alleviate fears and empower young patients to cope effectively.

Fostering Hope

Fostering hope was identified in 17 out of 80 interviews, showing lower interest in this function than others identified (Sisk et al., 2021). The concept of fostering hope may not have been identified in all cases because there are many types of cancer, treatment, and severities of conditions. Families with less severe types of cancer may not feel the need for this level of

support and care. Some families may find fostering hope a concept that is concerning to a young child if they feel the unknown or possible negative outcomes would be concerning to the child.

This literature review looked at both literacy and health literacy and how these concepts help families of childhood cancer patients process information and manage the complex situations found during childhood cancer. Clear communication, promoting building relationships with medical staff, and addressing emotions are all necessary steps to promote health literacy in pediatric oncology.

Chapter III: Methodology

The researcher completed a literature review on health literacy concepts in the context of medical patient education. This study has placed emphasis on the importance of healthcare communication during the diagnosis and treatment of childhood cancer.

As a mother of a childhood cancer survivor, the researcher and her family received invaluable information from three prominent national advocacy organizations. The researcher chose these organizations based on their impact and the availability of guidance documents for families dealing with childhood cancer. These organizations played a significant role in helping navigate the diagnosis and treatment of our child, providing us with information and support.

American Childhood Cancer Organization

The American Childhood Cancer Organization (ACCO) is the nation's oldest community of families, survivors, and friends affected by childhood and adolescent cancer, founded in 1970 by the parents of children diagnosed with cancer (American Childhood Cancer Organization, 2014). In 2014, ACCO published a 261-page guidebook titled "A Parent's Guide to Enhancing Quality of Life in Children with Cancer." As of March 8, 2024, the guidebook can be purchased online or downloaded for free in PDF format from their website.

Children's Oncology Group

The Children's Oncology Group (COG) is a non-profit organization committed to researching childhood and adolescent cancer (The Children's Oncology Group, 2011). COG's Family Handbook, published in 2011, is a comprehensive guidebook that contains valuable information for families dealing with childhood cancer (The Children's Oncology Group, 2011). The original handbook has three versions: a 184-page English version, a 190-page Spanish version, and a 190-page French version. COG has also published three translated versions of the

Family Handbook in Armenian, Chinese, and Korean (The Children's Oncology Group, 2011). For the current study, the researcher used the English version of the Family Handbook.

The COG has created a document called The New Diagnosis Guide. This guide is meant to be a quick start guide that contains the most important information from the family handbook for those who have recently received a diagnosis. There are three translations of this 20-page guide available in Arabic, Chinese, and Tamil. The COG documents can be accessed online for free for screen viewing via the Apple iBooks application, Amazon Kindle, and other eBook readers. COG-affiliated institutions can order printed copies through their website (The Children's Oncology Group, 2011).

National Pediatric Cancer Foundation

The National Pediatric Cancer Foundation (NPCF) is a non-profit organization that aims to fund research to eliminate childhood cancer. The organization was founded in 1991 by two mothers who met at the hospital after both of their infant daughters were diagnosed with cancer. For the first 15 years, the organization focused on working with hospitals in Florida, but since 2005, the NPCF has expanded its reach to collaborate with over 30 hospitals across the United States (National Pediatric Cancer Foundation, n.d, p. 4). In 2022, the researcher accessed the NPCF's 103-page guidebook, the Pediatric Cancer Toolkit, available for free download on the NPCF website. However, no publication date is provided for the guidebook.

Guidance Document Used for Analysis

“Simply Put: A guide for creating easy-to-understand materials” (Appendix A) from the Center for Disease Control and the US Department of Health and Human Services, published in 2009, was selected to analyze the three chosen guidance documents.

The CDC developed this guidance document to help transform complex scientific and technical information into easily understandable documents, making it an ideal choice for analyzing the guidance documents related to the diagnosis and treatment of childhood cancer (Centers for Disease Control and Prevention, 2009, p. 3).

After reviewing the CDC checklist guidelines to identify relevant categories and criteria for analysis, benchmarks were established, allowing for a structured analysis Centers for Disease Control and Prevention (2009). The benchmarks are structured on the guidance the CDC gave in *Simply Put*. The checklist includes six categories:

- message content
- text appearance
- visuals
- layout and design
- translation
- understandability

It's worth noting that the guidance document released by the CDC is intended for the creators of documents, not for the secondary analysis conducted in this study. As this study is a secondary analysis, the categories of translation and understandability have been left out. The translation category pertains to cultural appropriateness, which is beyond the scope of this study. The understandability category includes questions related to the complexity of the language and pre-and post-testing, which are not contained in this study (Centers for Disease Control and Prevention, 2009, p. 25). The analysis solely focuses on the materials that have already been developed.

The research process involved setting benchmarks for yes and no answers, followed by a review of the three selected handbooks. Checklists were completed to assess how closely each handbook adhered to CDC guidance and to identify trends within four analyzed categories: message context, text appearance, visuals, and layout and design. (See Appendix A). Once the checklists were completed, the researcher analyzed the data.

Category 1: Message Content

The message content category (see Table A1) contains six questions that help the author determine what they wish to convey and how to present it to the reader in a way that is easy to comprehend and act on (Centers for Disease Control and Prevention, 2009, p. 5).

- Have you limited your messages to three to four messages per document (or section)? (Centers for Disease Control and Prevention, 2009, p. 29).
 - The researcher will answer this quantitative question by counting the main messages within a section. The researcher concluded that if a section contains more than four messages, this question will be marked no.
- Have you taken out information that is “nice to know” but not necessary? (Centers for Disease Control and Prevention, 2009, p. 29).
 - The researcher has determined that the answer to this qualitative question will be found by reviewing the provided information and determining if each section contains any irrelevant information that is not required to comprehend the main message. If most of the sections contain extraneous details, the answer will be marked as no. For instance, when defining cancer, including information about who first discovered it and on what date would be considered nonessential.

- Is the most important information at the beginning of the document? (Centers for Disease Control and Prevention, 2009, p. 29).
 - The researcher concluded that the table of contents is a summary of a document listing chapters and sections in order. This question will be marked no if primary information is not included first versus extraneous details.
- Is it repeated at the end? (Centers for Disease Control and Prevention, 2009, p. 29).
 - The researcher found that a summary included at the end of the document would result in a yes answer.
- Have you identified action steps or desired behaviors for your audience? (Centers for Disease Control and Prevention, 2009, p. 29).
 - The researcher determined that this question will be marked yes when action steps such as calling the doctor or scheduling an appointment are included in the document.

Category 2: Text Appearance

The text appearance content category contains nine questions that can assist writers in enhancing the readability of their work (see Table A2).

- Does your document have lots of white space? (Centers for Disease Control and Prevention, 2009, p. 29).
 - The researcher concluded this question would be marked no if 95% of pages were solid text with little white space.
- Are margins at least 1/2 inch? (Centers for Disease Control and Prevention, 2009, p. 29).

- This quantitative question will be answered based on measuring the margins. Margins less than ½ inch will be marked no.
- Is the print large enough (at least 12 points)? (Centers for Disease Control and Prevention, 2009, p. 29).
 - This quantitative question will be answered based on measuring the font. The researcher determined that this question would be answered no if the font size exceeded 12 points.
- Does it have serifs? (Centers for Disease Control and Prevention, 2009, p. 29).
 - Serifs are fonts with decorative lines, such as Times New Roman. The researcher will answer yes if the font has serifs.
- Have you used bold, italics, and text boxes to highlight information? (Centers for Disease Control and Prevention, 2009, p. 29).
 - The researcher determined the question would be answered yes if any text emphasis methods were used, such as bold or italics in the document's main text.
- Have you avoided using all capital letters? (Centers for Disease Control and Prevention, 2009, p. 29).
 - The researcher found the question will be marked yes if the only bold characters used are in titles, headings, or subheadings and not in the main body of the text.
- Is text justified on the left only? (Centers for Disease Control and Prevention, 2009, p. 29).

- The researcher has determined that this question will be marked yes if the main body text is left-justified. The title page and headings are excluded.
- Did you use columns with a line length of 40 to 50 characters of space? (Centers for Disease Control and Prevention, 2009, p. 29).
 - The researcher found that this question is quantitative and can be measured. The question will be marked no if more than 50 characters are in a row.

Category 3: Visuals

The visuals category (see Table A3) contains eight questions that can help document creators grab the audience's attention and tell a story, such as the steps involved in a procedure like drawing blood (Centers for Disease Control and Prevention, 2009, p. 10).

- Is the cover attractive to your intended audience? (Centers for Disease Control and Prevention, 2009, p. 29).
 - The person conducting the research is the mother of a childhood cancer survivor. She belongs to the target audience, which consists of the families and caregivers of children diagnosed with childhood cancer. The researcher has decided that the question will be considered affirmative if the cover design appeals to the intended audience based on her personal experience. This benchmark is subjective to the researcher's opinion.
- Does it include your main message and show who the audience is? (Centers for Disease Control and Prevention, 2009, p. 29).
 - The researcher is a target audience member and decided that if she felt the cover and title were relatable, this question would be marked as yes. This benchmark is subjective to the researcher's opinion.

- Are your visuals simple and instructive rather than decorative? (Centers for Disease Control and Prevention, 2009, p. 29).
 - The researcher has established that a question should be marked as yes if the graphics accompanying it provide instructional content, such as the steps to a procedure or an anatomy diagram. On the other hand, if the visuals are not related to the handbook's content, for instance, clip art flowers or an abstract design, then the question should be marked as no.
- Do visuals help explain the messages found in the text? (Centers for Disease Control and Prevention, 2009, p. 29).
 - The researcher determined that this question would be marked yes if the visuals explained the text near it, such as an anatomy diagram and an explanation about inserting an IV.
- Are your visuals placed near related text? (Centers for Disease Control and Prevention, 2009, p. 29).
 - The researcher found that this question will be answered yes if the visuals match the content near it, such as a skeleton system with labeled parts next to a description of the types of cancer and where they appear.
- Do they include captions? (Centers for Disease Control and Prevention, 2009, p. 29).
 - The researcher concluded that captions should be included with most visuals. A few missing captions are acceptable as long as they follow this guidance. This question will be marked yes if 95% of visuals include an accompanying caption.

- If you read only the captions, would you learn the main points? (Centers for Disease Control and Prevention, 2009, p. 29).
 - The researcher decided this question would be marked yes if the captions included the main topics. It will be marked no if most of the main points are not included in captions.

Category 4: Layout and Design

The layout and design category (see Table A4) contains eight questions designed to make the documents straightforward to understand and appealing to the intended audience (Centers for Disease Control and Prevention, 2009, p. 17).

- Is information presented in an order that is logical to your audience? (Centers for Disease Control and Prevention, 2009, p. 29).
 - The researcher marked this question as yes if the topic flow appears logical, such as providing information on diagnosis first, then treatment, and finishing with aftercare. Another example includes the sequence from caring for a living child to addressing the transition and management of a child passing away. This benchmark is subjective to the researcher's opinion.
- Is information chunked, using headings and subheadings? (Centers for Disease Control and Prevention, 2009, p. 29).
 - The researcher determined this question would be marked yes if the main text were broken into distinct logical sections, including headings and subheadings.
- Do lists include bullets? (Centers for Disease Control and Prevention, 2009, p. 29).

- The researcher decided this question would be answered yes if most lists included bullet points.
- Have you eliminated as much jargon and technical language as possible? (Centers for Disease Control and Prevention, 2009, p. 29).
 - The researcher concluded that using clear and concise language, without technical jargon and unnecessary rambling, will result in a yes answer to the question. For example, the CDC's "Simply Put" guidance uses the example of high blood pressure instead of hypertension.
- Is technical or scientific language explained? (Centers for Disease Control and Prevention, 2009, p. 29).
 - Based on the researcher's findings, this question will receive a yes answer if definitions are included in the main text or a glossary of uncommon or medical language terms.
- Have you used concrete nouns, an active voice, and short words and sentences? (Centers for Disease Control and Prevention, 2009, p. 29).
 - The question will be marked as yes if most of the text incorporates these concepts. For example, sentences should use active voice, such as the child-life specialist sang a song instead of a song was sung by the child-life specialist. Words should be kept to one or two syllables. Sentences should be between eight and ten words, if possible. Paragraphs should be three to five sentences on average.
- Is the style conversational? (Centers for Disease Control and Prevention, 2009, p. 29).

- The researcher decided to mark this question as yes if most of the text is conversational, as if someone is speaking directly to the audience. For example, writing messages as if you were talking to a friend, you could get sick during or after treatment. This benchmark is subjective to the researcher's opinion.

Chapter IV: Results

This aim of this study was to determine if the handbooks given to the family of children diagnosed with cancer during a diagnosis were created to easily allow the readers to comprehend and follow. The American Childhood Cancer Organization, Children's Oncology Group, and the National Pediatric Cancer Foundation created the handbooks analyzed during this study. These organizations support the patients and families of children diagnosed with cancer. The guidebooks were assessed focusing on four main categories: message content, text appearance, visuals, and layout and design. These categories helped determine how well the handbooks conveyed information to the parents of children diagnosed with cancer. The following results have been identified by analyzing the handbooks against the established benchmarks.

Category 1: Message Content

The message content category contained six questions that help the author determine what they wish to convey and how to present it to the reader in a way that is easy to comprehend and act on (Centers for Disease Control and Prevention, 2009, p. 5).

Overall Section Results

After analyzing the scores of all three handbooks across the message content category, the handbooks met 40% of the benchmarks overall.

American Childhood Cancer Organization

The ACCO met 40% of the guidelines in the message content category, but it didn't meet the benchmarks for limiting the number of messages. The handbook chapters are complex, providing a lot of information concisely and straightforwardly. However, the handbook failed to meet the benchmark for limiting unnecessary information. Even though the family perspective section following each chapter gives real-life examples and advice to the parents or caregivers

reading the publication, the handbook does not repeat the information at the end due to the complex nature of a cancer diagnosis.

Although there are small summaries after some content areas, there is no summary at the end of the publication. It is too much information to summarize the whole publication. The handbook does an excellent job of identifying action steps and providing a long list of tribute ideas if a child passes away. It also offers an exhaustive list of symptoms, including the cause, how it presents itself, what treatment you can do at home, what possible medications can help, and when to call the doctor.

Children's Oncology Group

The content of the message from the COG met only 40 % of the guidelines. The benchmarks for limiting the number of messages and unnecessary information were not achieved. Although the handbook's chapters are complex and have a lot of information, it includes details that may not apply to everyone. However, they are still helpful to know in case they apply to your situation, as cancer is a complicated disease with many types. The handbook has a logical flow, starting with information on when to call for help, followed by information on hospitals, general information about cancer, types of cancers, tests and procedures, treatment and its effects, caring for your child, and after-treatment care. At the end of the publication, there is an extensive glossary of keywords. Several resources are available to help identify steps or desired behaviors, such as sections asking what questions you should ask and instructions to call your doctor if you experience a list of symptoms.

National Pediatric Cancer Foundation

The NPCF handbook only met 40% of the guidelines for message content, but it did well in limiting unnecessary information. However, it failed to meet the benchmarks for restricting

the number of messages. Compared to other handbooks, the NPCF handbook was more concise. Although, it doesn't have the essential information at the beginning, which should have been there according to the CDC guidance. The publication started with resources for record-keeping, such as question lists for doctors, blank calendars to track dates, food logs, exercise logs, and note pages. These resources should have been added at the end of the document after explaining the processes. The publication included lists of actions such as questions to ask children, questions to ask medical professionals, and coping skills for difficult situations.

Category 2: Text Appearance

The text appearance content category included nine questions that can help writers improve the readability of their work.

Overall Section Results

After analyzing the scores of all three handbooks across the text appearance category, the handbooks met all of the benchmarks overall.

American Childhood Cancer Organization

The ACCO handbook met all the benchmarks in this category. The margins are at least ½ inch, but there is little white space. The pages contain mostly plain text without visuals. Text was highlighted by using text boxes throughout the chapters. The font was large enough to be easy to read, but it does have serifs. The chapter titles, author's names, and text boxes were in a sans-serif font, but most of the chapter's text was in a font with serifs. The table of contents contained bolded chapter titles. The chapter and subchapter titles were bold. References to other sections of the publication were bold. Text boxes throughout the handbook highlighted vital topics and explain individual contributor's backgrounds. Italics were used when adding comments from specific parent's or caregiver's experiences. Text boxes were used to highlight important

information. The publication cover and the title page contained the title and authors in all capital letters. The rest of the text was in the traditional format of the uppercase first letter of the sentence, and the rest was lowercase. All text was left-justified throughout the publication in the main text. The text in the text boxes was also left justified. The only center-justified text was on the cover pages, title page, and dedication page. The text was in a traditional format in a column, with most rows around 50 characters long.

Children's Oncology Group

The COG handbook met all the benchmarks in this category. The document had at least ½-inch-wide margins and used white space to break up the text. The print was large enough for easy reading, and a mix of serif and sans-serif text was used for the document titles, headings, and main text. Bold, italics, and text boxes emphasized the headings and important information. The chapter titles and subheadings were all in capital letters. Most of the text was in the traditional format of the uppercase first letter of the sentence, and the rest was lowercase. All the main text was left-justified, and the text was in a traditional format in a column, with most rows of text being less than 50 characters long.

National Pediatric Cancer Foundation

The NPCF handbook met all the benchmarks in this category. The publication was designed with ample white space and graphics that help break up large blocks of text. The margins were set at least ½ inch wide. The font size was large and easy to read, while the text utilizes sans-serif fonts that made it clear and straightforward. The publication also used bold, italics, and text boxes to highlight important information. Chapter titles were all in capital letters, while some infographics and captions also contained all capital letters. The rest of the text followed a traditional format of using uppercase first letters for each sentence, and the rest was in

lowercase. All main text was left-justified, while the text included in infographics was center-justified. The text was organized in a column, with most rows less than 50 characters long.

Category 3: Visuals

The visuals category contained eight questions that can help document creators grab the audience's attention and tell a story, such as the steps involved in a procedure like drawing blood (Centers for Disease Control and Prevention, 2009, p. 10).

Overall Section Results

After assessing the scores of all three handbooks in the visuals category, it was found that the handbooks met 73.3% of the benchmarks overall.

American Childhood Cancer Organization

The ACCO met 80% of the guidelines in the visuals category. The publication's cover was attractive and relevant to its intended audience - families and caregivers of children with cancer. The cover featured a parent holding a child's hand, an eye-catching image for the intended audience. The title of the publication, "A Parent's Guide to Enhancing the Quality of Life in Children with Cancer," clearly stated the intent and target audience. The visuals were simple, not decorative, and there were very few visuals in the publication. The front and back cover and the title page contained two images. One image was of an adult holding a child's hand, and the other was a photo of a small child's head from the back. The remainder of the publication consisted of solid text with text boxes. There are no unnecessary graphics or colors. The document had a simple design and was intended to be instructive. The visuals included in the publication helped to explain the messages. While there are few visuals, the two included made a significant statement on the cover and title pages. The visuals were placed near the related text of the title of the publication and do not include any captions other than the title and authors.

Children's Oncology Group

The COG met 80 % of the guidelines in the visuals category. The publication's cover had simple graphics identifying the author, the title, and the target audience as a family handbook. The visuals were simple yet instructive. Although there are some decorative visuals, they were minimal. There were plenty of helpful graphics that display body parts and procedures, and they assisted in explaining the accompanying text. The graphics placed near the relevant text, and most of them include captions.

National Pediatric Cancer Foundation

The NPCF met 60% of the guidelines in the visuals category. The cover had a cheerful and upbeat appearance with red, orange, and yellow graphics. The inside cover had the same color scheme and features a happy child. The title of the publication, "Pediatric Cancer Toolkit," conveyed the main message and provided a vague description of the target audience with the text "Your guide." However, the visuals did not meet the benchmark for being straightforward and instructional. The publication included decorative pages such as the cover page, chapter title pages, and the table of contents. Many of the pages had graphics for decoration. There were a lot of infographics to explain the messages found in the main text, and they were placed near the related text. They included captions, for example, photos of children with their names, ages, and diagnoses. However, only reading the captions did not cover all the information in the publication. All information did not have related visuals, so it is essential to read the main text to learn all the main points.

Category 4: Layout and Design

The layout and design category contained eight questions designed to make the documents accessible and appealing to the intended audience (Centers for Disease Control and Prevention, 2009, p. 17).

Overall Section Results

After analyzing the scores of all three handbooks across the layout and design category, the handbooks overall met 94.4% of the benchmarks. This category ranked second highest for meeting benchmarks.

American Childhood Cancer Organization

The publication created by ACCO has successfully met all the guidelines in the layout and design category. The content of the publication was arranged in a logical order, starting with the management of a cancer patient's life, followed by discussions on what could happen if the worst occurs. Finally, the publication concluded with a list of resources for more information. Headings and subheadings were used to break the information into easily manageable sections. Lists within chapters were numbered and did not use bullets, while lists in breakout text boxes were bulleted. The language used in the publication was easy to understand and did not require a medical background to comprehend. Keywords were defined throughout the text as introduced, and concrete nouns like sight, smell, hearing, touch, and taste are used to describe situations. Passive voice was used in text parts when parents explain their experiences and give advice. Sentences were mostly short and do not contain complicated phrases or words. The writing style was conversational, and stories from parents who have been through similar situations were integrated into the text to make it feel like a conversation with the reader.

Children's Oncology Group

The COG met 100 % of the guidelines in the layout and design category. It had a logical flow of information, starting with when to call for help, information on hospitals, general information about cancer, types of cancers, tests and procedures, treatment and effects, caring for your child, and after treatment ends. The publication ends with an extensive glossary of keywords. The information was organized with headings, subheadings, and bulleted lists, making it easy to read and understand. The text did not require any medical background to be understood. It used concrete nouns, such as sight, smell, hearing, touch, and taste, to describe concepts. Active voice was often used, and sentences are primarily short without complicated phrases and words. The text used a conversational style to explain concepts clearly.

National Pediatric Cancer Foundation

The NPCF met 83% of the guidelines in the layout and design category. The only missed benchmark was the logical order of the information presented to the audience. The handbook could be improved by placing the documents that the publication starts with at the end, as it would make more sense. The publication included record-keeping information such as doctor question lists, blank calendars to track dates, food logs, exercise logs, and note pages. It did an excellent job of categorizing information with headings, subheadings, and bulleted lists with multiple levels. The content was easy to read, and it doesn't require a medical background to understand it. Keywords were defined throughout the text, and concrete nouns such as sight, smell, hearing, touch, and taste describe the topics. The majority of the sentences were short and do not contain complicated phrases and words. The text employed a conversational style to explain concepts, which is easy to follow.

Final Overall Results

Here are the final analysis results for each handbook. The final analysis revealed a 9.1% performance gap between the best and worst-performing handbook. This narrow window shows that all three handbooks are developed following a significant amount of the guidelines between 72.7% and 81.8%.

American Childhood Cancer Organization

The ACCO childhood cancer guidebook was evaluated against four categories, and it met all benchmarks in two of them. However, it did not meet all the benchmarks in the message content and visuals categories. Specifically, it missed one benchmark in the visuals category, which required the captions to convey the main points. No guidebook was able to meet this benchmark due to the complexity of the documents.

Children's Oncology Group

The COG childhood cancer guidebook met all benchmarks in two of four categories. The two categories where they did not meet all the benchmarks were in the message content and visuals categories.

National Pediatric Cancer Foundation

The NPCF childhood cancer guidebook met all benchmarks in one of four categories. The three categories where they did not meet all the benchmarks were the message content, visuals, and layout and design categories. NPCF was the only guidebook not to achieve all of the benchmarks in the layout and design category. The benchmark was missed because the information presented was not in a logical order. The researcher noted that it would have made more sense to include the documents the publication starts with at the end. The publication begins with record keeping, such as question lists for doctors, blank calendars to track dates,

food logs, exercise logs, and note pages. The NPCF handbook was the only one to meet the benchmark of having you take out information that is nice to know but unnecessary. The researcher found this was true because this publication is more concise than the other documents reviewed.

Overall All Section Results

After analyzing the scores of all three handbooks across all categories, the researcher found an overall benchmark success rate of 63.6%.

Research Questions

The goal of this study was to analyze the information given to childhood cancer patients and their families as they navigate the diagnosis, treatment, and life after childhood cancer.

Research Question

The research question asked, “How do childhood cancer advocacy organizations incorporate health literacy concepts in their family handbook guidance documents?”

Chapter V: Discussion, Conclusions, and Recommendations

After conducting a literature review on literacy, health literacy, and clear communication within the context of childhood cancer, an analysis was completed to determine how closely three childhood cancer organizations used health literacy concepts. These are the researcher's findings.

Discussion

The CDC's checklist in the "Simply Put" document was an effective tool for analyzing of the three childhood cancer family guidebooks. The following discussion focuses on the common themes and handbooks that stood out in each category according to the established benchmarks. In evaluating the message, visuals, and layout and design categories of the CDC's "Simply Put" checklist in the context of childhood cancer, it's essential to acknowledge the subjectivity inherent in the benchmarks (Centers for Disease Control and Prevention, 2009, p. 29). These benchmarks were established based on the researcher's family's personal experiences as a with childhood cancer. Therefore, the criteria to assess these sections reflect individual perspectives formed by the researcher's experiences. This subjectivity means that other parents or readers, whether they have encountered childhood cancer or not, may approach these benchmarks differently. Other interpretations and answers to questions about message effectiveness, visual appeal, and design functionality could vary significantly, highlighting a diverse range of perspectives and experiences.

Category 1: Message Content

According to the researcher, the message category was the most challenging for the publications to meet the guideline benchmarks. The researcher believes this is because the guidelines might not have been intended to be used with such large documents in mind.

Guidelines like limiting messages to three or four per section or document do not consider the complicated nature of childhood cancer guidance documents (Centers for Disease Control and Prevention, 2009, p. 5). No guidebook analyzed met this guideline. Another guideline no guidebook achieved was the information repeated at the end. The benchmark associated with the question of have you taken out information is nice to know but not necessary is subjective and based on the researcher's experiences with childhood cancer.

The ACCO guidebook stands out for combining practical advice through its inclusion of family perspective sections supplementing each chapter. These sections serve as a helpful resource to parents and families dealing with the complexities of childhood cancer. For families facing the daunting reality of a child's diagnosis and subsequent treatment, these real-life examples and guidance become essential in navigating the unknown terrain. For instance, transitioning from hospital care to home care after diagnosis. When returning home after treatment, the task of discerning between worrisome symptoms warranting immediate medical attention and the expected side effects of treatment becomes challenging to manage. The ACCO guidebook's family perspective sections offer personal experiences and practical approaches to navigate these challenges. Through shared narratives and expert advice, families can find reassurance, knowing they are not alone.

One notable aspect setting COG apart is their "The New Diagnosis Guide," a concise resource designed as a quick start guide for families struggling with a recent childhood cancer diagnosis. Providing crucial information from the complete handbook, this 20-page document offers immediate support and guidance to families during the challenging early stages of diagnosis. What's particularly commendable is the accessibility of this resource, with translations available in Arabic, Chinese, and Tamil. This initiative ensures that families from diverse

linguistic backgrounds can access essential information in a format that resonates with them, underscoring COG's commitment to providing comprehensive support to families facing childhood cancer.

Category 2: Text Appearance

This category is unique because it is the only category that all three handbooks that meets all the guidelines for text appearance. The researcher believes this is because the guidelines and associated benchmarks are more accessible to achieve than those in other categories. Standard practices, such as having at least a half inch of white space and using a 12-point font, make hitting these benchmarks easy. Unlike other categories, most guidelines are quantitative and can be measured.

Despite varying in length, ranging from 103 to 261 pages, none of the handbooks showed a clear correlation between their page count and their ability to meet the benchmarks set for a valuable resource for families facing childhood cancer. Regardless of their size, each handbook contained a lot of information, support, and guidance essential for families navigating the complexities of childhood cancer.

Category 3: Visuals

All three handbooks failed to meet the benchmark for reading the captions to understand all the main points. The researcher believes that this is because the content is complex. Additionally, one benchmark was missed by one handbook only, which is whether the visuals are simple and instructive and not merely decorative.

COG distinguishes itself in the visuals category through its comprehensive handbook, filled with numerous helpful illustrations. These visuals are invaluable aids in explaining complex concepts such as organ placement and the skeletal system. COG's handbook provides

detailed depictions of medical procedures, ranging from spinal taps to bone marrow draws, enhancing understanding for readers. Moreover, the handbook illuminates the complexities of external line placement for PICCs and internal line placement for ports, offering a better understanding in addition to the chapter's text. Through attention to visual representation, COG ensures that its handbook stands out as a resource for medical professionals and the families of childhood cancer patients navigating the intricacies of pediatric oncology.

Category 4: Layout and Design

The researcher discovered that the benchmarks in this category were easy to meet, much like the text appearance category, because the concepts were relatively simple and common practices. One handbook missed one benchmark due to information presented out of order for the target audience. Otherwise, this category was completely successful.

In the category of layout and design, both COG and ACCO have exceeded expectations by meeting all the benchmarks and demonstrating their user-centric approach. However, NPFC failed to meet only one benchmark out of six as its information was not organized logically for the audience. Although each of the three handbooks has unique design elements, none stood out. All three handbooks successfully meet the majority of the benchmarks in this category.

Conclusions

The family handbooks analyzed during this study are a great resource for the families of childhood cancer patients. The handbooks offer a level of support for the families outside of the hospital and clinic. They include practical information and guidance in hard times when families can feel overwhelmed with information. Giving families access to this level of support and information empowers them to manage their families difficult journey.

After analyzing three childhood cancer guidebooks, each handbook has both strengths and weaknesses. Despite variations in being able to meet the benchmarks, each handbook met many of the guidelines established by the CDC.

The ACCO handbook stood out for meeting all benchmarks in the layout and design category. It didn't meet the benchmarks in the message content and visuals categories identifying the opportunity for improvement in clarity. The COG handbook did well in design and layout but met less benchmarks in the visuals and content categories. The NPCF guidebook had its own strengths. It met the fewest benchmarks but successfully limited information but did not have a logical order.

One significant inconsistency was found over the availability and accessibility of the handbooks. The ACCO and NPCF provide guidebooks online, but only offer an English version. In contrast the COG stands apart offering many versions in different languages. The COG sets itself apart by making the guidebooks available in many formats providing accessibility like no other organization. It is impressive the COG provides these resources for free. The COG has established themselves as holding a high-level commitment to disseminating information to families across the globe.

As a parent affected by childhood cancer, the handbooks my family received during the diagnosis and treatment were a valuable reference when we were in the hospital, clinic, or at home. The handbook provided needed support during a very difficult year. At home we would consult them to get ready for doctor visits or treatment. They also became useful to explain complex situations to our family and friends.

In conclusion, analyzing the three childhood cancer guidebooks against CDC benchmarks allowed the researcher to determine how valuable of a resource these guidebooks are to the

families of childhood cancer patients. While all handbooks were notable for meeting a significant amount of the benchmarks, COG stood out as the clear winner for providing accessibility and availability of information to families worldwide.

Recommendations

Families facing challenging medical diagnoses should find available resources from health literacy and childhood cancer advocacy organizations. These organizations are equipped to help provide families the resources they need. Families can also reach out to the medical professionals or social workers to find local or national resources available to them.

Another suggestion is for the three organizations to make it a priority to review and update their handbooks regularly to reflect the latest and most effective best practices and changes to procedures. Furthermore, the researcher recommends that businesses or organizations looking to create or update documentation identify guidelines or benchmarks to follow to create clear and accessible documentation. Using guidelines will allow future documents to update the documents as needed when communication or public health recommendations change. Providing the childhood cancer community the best documentation possible.

Recommendations for Future Studies

This study acknowledges that the audience of a childhood cancer guidebook is diverse, consisting of people of different races, nationalities, and languages spoken. Furthermore, we cannot assume that all readers of these guidebooks live in the United States, as these guidebooks are available online. A potential study could explore the cultural appropriateness of the content for specific groups, ensuring that it is relevant and accessible.

Certain cultural and religious beliefs can significantly influence the rejection of medical interventions. For instance, some people decline blood transfusions due to religious beliefs

(Linnard-Palmer, L. & Kools, S., 2005). Similarly, some cultures may have skepticism towards Western medicine, preferring traditional or alternative healing methods (American Cancer Society, n.d.). Understanding these religious and cultural differences is crucial for healthcare providers to foster effective communication and respect patients' beliefs while ensuring the delivery of appropriate medical care.

To validate the findings of this research, the researcher proposes conducting another study focusing on human subjects testing to survey the benchmarks established in the initial research. Involving other parents of children with cancer would help determine if these individuals would establish similar benchmarks. This duplicate study would scrutinize whether the benchmarks derived from the initial research are consistent across a broader audience. This approach not only ensures the reliability of this study but also adds depth to the understanding of childhood cancer communication strategies.

References

American Cancer Society. (n.d.). *What is alternative medicine?*

<https://www.cancer.org/cancer/managing-cancer/treatment-types/alternative-medicine/what-is-alternative-medicine.html>

American Childhood Cancer Organization (2014). *A parent's guide to enhancing quality of life*

in children with cancer (R. Hoffman & S. E. Smith, Eds.). <https://www.acco.org/wp-content/uploads/2020/11/Enhancing-Quality-of-Life-small-compressed.pdf>

Centers for Disease Control and Prevention. (2009). *Simply put: A guide for creating easy-to-understand materials* (3rd ed.). U.S. Department of Health and Human Services.

https://www.cdc.gov/healthliteracy/pdf/Simply_Put.pdf

Centers for Disease Control and Prevention. (n.d.). What is health literacy? U.S. Department of

Health and Human Services. <https://www.cdc.gov/healthliteracy/learn/index.html>

Linnard-Palmer, L., & Kools, S. (2005). Parents' refusal of medical treatment for cultural or religious beliefs: An ethnographic study of health care professionals' experiences.

Journal of Pediatric Oncology Nursing, 22(1), 48-57.

<https://doi.org/10.1177/1043454204270263>

National Cancer Institute. (n.d.-a). Cancer. In *NCI Dictionary of Cancer Terms*.

<https://www.cancer.gov/publications/dictionaries/cancer-terms/def/cancer>

National Cancer Institute. (n.d.-b). Childhood Cancer. In *NCI Dictionary of Cancer Terms*.

<https://www.cancer.gov/publications/dictionaries/cancer-terms/def/childhood-cancer>

National Cancer Institute. (n.d.-c). Child Life Specialist. In *NCI Dictionary of Cancer Terms*.

<https://www.cancer.gov/publications/dictionaries/cancer-terms/def/child-life-specialist>

National Cancer Institute. (n.d.-d). Diagnosis. In *NCI Dictionary of Cancer Terms*.

<https://www.cancer.gov/publications/dictionaries/cancer-terms/def/diagnosis>

National Cancer Institute. (n.d.-e). Nurse. In *NCI Dictionary of Cancer Terms*.

<https://www.cancer.gov/publications/dictionaries/cancer-terms/def/nurse>

National Cancer Institute. (n.d.-f). Oncologist. In *NCI Dictionary of Cancer Terms*.

<https://www.cancer.gov/publications/dictionaries/cancer-terms/def/oncologist>

National Cancer Institute. (n.d.-g). Oncology. In *NCI Dictionary of Cancer Terms*.

<https://www.cancer.gov/publications/dictionaries/cancer-terms/def/oncology>

National Cancer Institute. (n.d.-h). Social Worker. In *NCI Dictionary of Cancer Terms*.

<https://www.cancer.gov/publications/dictionaries/cancer-terms/def/social-worker>

National Cancer Institute. (n.d.-i). Treatment Plan. In *NCI Dictionary of Cancer Terms*.

<https://www.cancer.gov/publications/dictionaries/cancer-terms/def/treatment-plan>

National Center for Education Statistics. (n.d.). *Program for the international assessment of adult competencies (PIAAC): What PIAAC measures*. U.S. Department of Education.

<https://nces.ed.gov/surveys/piaac/literacy.asp>

National Pediatric Cancer Foundation. (n.d.). Pediatric cancer toolkit: Your guide.

<https://nationalpcf.org/wp-content/uploads/2022/09/Pediatric-Cancer-Toolkit-Your-Guide-National-Pediatric-Cancer-Foundation-2022.pdf>

Polakova, K., Ahmed, F., Vlckova, K., & Brearley, S. G. (2024). Parents' experiences of being involved in medical decision-making for their child with a life-limiting condition: A systematic review with narrative synthesis. *Palliative Medicine*, 38(1), 7–24.

Sisk, B. A., Schulz, G. L., Blazin, L. J., Baker, J. N., Mack, J. W., & DuBois, J. M. (2021).

Parental views on communication between children and clinicians in pediatric oncology:
a qualitative study. *Supportive Care in Cancer*, 29, 4957–4968.

The Children's Oncology Group. (2011). *Family handbook for children with cancer* (2nd ed.).

https://childrensoncologygroup.org/downloads/English_COG_Family_Handbook.pdf

Appendix A

Handbook Analysis Results

Comparing American Childhood Cancer Organization (ACCO), Children’s Oncology Group (COG), and the National Pediatric Cancer Foundation (NPCF) handbooks to guidelines in the CDC Document “Checklist for Easy-to-Understand Print Materials” in “Simply Put: A Guide for Creating Easy to Understand Materials. (CDC, 2009 p.29)

Table A1

Analysis of Category 1: Message Content

Guideline	ACCO	COG	NPCF
Have you limited your messages to three to four messages per document (or section)?	No	No	No
Have you taken out information that is “nice to know” but not necessary?	No	No	Yes
Is the most important information at the beginning of the document?	Yes	Yes	No
Is it repeated at the end?	No	No	No
Have you identified action steps or desired behaviors for your audience?	Yes	Yes	Yes

Table A2*Analysis of Category 2: Text Appearance*

Guideline	ACCO	COG	NPCF
Does your document have lots of white space? Are margins at least 1/2 inch?	Yes	Yes	Yes
Is the print large enough (at least 12 points)? Does it have serifs?	Yes	Yes	Yes
Have you used bold, italics, and text boxes to highlight information?	Yes	Yes	Yes
Have you avoided using all capital letters?	Yes	Yes	Yes
Is text justified on the left only?	Yes	Yes	Yes
Did you use columns with a line length of 40 to 50 characters of space?	Yes	Yes	Yes

Table A3*Analysis of Category 3: Visuals*

Guideline	ACCO	COG	NPCF
Is the cover attractive to your intended audience?	Yes	Yes	Yes
Does it include your main message and show who the audience is?	Yes	Yes	Yes
Are your visuals simple and instructive rather than decorative?	Yes	Yes	No
Do visuals help explain the messages found in the text?	Yes	Yes	Yes
Are your visuals placed near related text? Do they include captions?	Yes	Yes	Yes
If you read only the captions, would you learn the main points?	No	No	No

Table A4*Analysis of Category 4: Layout and Design*

Guideline	ACCO	COG	NPCF
Is information presented in an order that is logical to your audience?	Yes	Yes	No
Is information chunked, using headings and subheadings? Do lists include bullets?	Yes	Yes	Yes
Have you eliminated as much jargon and technical language as possible?	Yes	Yes	Yes
Is technical or scientific language explained?	Yes	Yes	Yes
Have you used concrete nouns, an active voice, and short words and sentences?	Yes	Yes	Yes
Is the style conversational?	Yes	Yes	Yes