PRODUCTION OF AN EVIDENCE-BASED PATIENT INFORMATION DOCUMENT IN THE FORM OF A CANCER PATIENT MANUAL OUTLINING CANCER ETIOLOGY, TREATMENT, AND TERMINOLOGY

by

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Abstract

The paper discusses the application and use of communication practices, principles, and theories in the production of an evidence-based patient information document that bridges recognized communication gaps between health care providers and patients with cancer. Cancer history and healthcare evolution are briefly addressed, along with more detailed analysis of documented differences and discrepancies in perception and experience between health care providers and patients with cancer. The paper discusses the production of a patient manual outlining cancer etiology (cause), treatment, and terminology with explanation of evidence-based rationale for choices in content and design to meet the needs of the target population based on research and review of related literature. An analysis and review of examples of industry-standard patient information documents from four major United States' cancer centers is included. The production process is discussed, along results of readability tests and a mid-stage usability study of the document.

Keywords: cancer, communication theory, patient information document, evidence-based

Dedication

I would like to dedicate this thesis project to the more than 1.6 million people in the United States, who were diagnosed with cancer in 2012, and to the health care providers care for them.

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Table of Contents

List of Tables

List of Figures

1. Introduction to the Project

Patients facing a cancer diagnosis and seeking treatment within the realm of Western medicine are indoctrinated into a discourse community of health care providers with its own medically-based language, treatment, personnel, and perspectives specific to the disease. The production of an evidence-based patient information document in the form of a printed manual for patients with cancer, which outlines disease etiology (cause and origin of the disease), treatment, and terminology, while taking into account the patient's perspective of the disease, is a direct application of communication science that serves to bridge communication gaps between health care providers and patients and has the potential to improve the patient experience.

For the purpose of this paper, from this point forward, the term "healthcare provider" will be referred to as "provider," and the phrase "patient with cancer" will be referred to as "patient."

Often, the first exposure people have to the specialty of oncology (which focuses on the treatment and management of cancer) is in the patient role. From the beginning of the provider-patient relationship, a huge discrepancy exists between the provider's and the patient's knowledge, understanding, perspective, and vocabulary, as associated with cancer. This gap creates an inherent communication problem, overshadowed by semiotic differences in interpretation of the language of cancer by the provider and the patient.

While the provider sees cancer as a medical problem to be analyzed through its etiology, diagnosis, and treatment, the patient experiences cancer from an emotional and physical level, revolving around fear of pain and death, and feelings of loss of control (Donnelly, 1995).

Primarily, the project discussed in this paper addresses the informational barriers to effective communication between provider and patient and how a patient information document can assist in bridging communication gaps.

Secondly, the document addresses semiotic differences in the interpretation of the language of cancer by taking into account differences in perspective between the provider and patient. Cancer-related information serves to remove certain negative aspects of the cancer patient's emotional experience in two ways: one, the information helps to eliminate fear of the unknown (Donnelly, 1995), and two, through its format, the document allows the patient to control access to the information, eliminating some feelings of loss of control (Kleinman, 1988).

Thirdly, the document uses communication theory and document design principles to make content and design choices that address the psychological and emotional concerns related to fear and loss of control (Donnelly, 1995). Decisions regarding choice of medium, document design, color choices, font, and images are based in communication science with a goal of presenting the information in a format created to counter the feelings of fear and loss of control experienced by cancer patients.

Throughout the paper, I provide further and more detailed support of how this project serves to bridge the communication gap between patient and provider, while quelling patient fear and anxiety, and facilitating an environment more amenable to communication, shared dialog, and discourse between patient and provider (Kleinman, 1988).

Lastly, the readability, functionality, and utility of the patient information document is evaluated, through the use of readability testing and a mid-stage usability study, which involved volunteer participants who have experienced a cancer diagnosis and various cancer treatments. The patient information document is included in Appendix A, and has been designed for a fictitious medical center, called, "Western Valley Medical Center."

2. Background to the Project

Evidence suggests that cancer has existed as an illness as long as there have been animals made up of cells capable of mutation and unchecked growth (Mukherjee, 2010). Sontag (1977) eloquently captures the inevitability of illness in the human condition, when she states: "Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship in the kingdom of the well and in the kingdom of the sick. Although we prefer only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place."

The evolution of cancer and many other illnesses has paralleled the evolution of man and the evolution of healthcare, including provider and patient perspective concerning disease and treatment.

2.1. Brief History of Cancer and Cancer Treatment

To better understand the provider and patient perspectives of cancer, it helps to understand some of the history of the disease. Mukherjee (2010) presented a thorough history of cancer from a medical perspective starting with paleontological evidence up to state-of-the art targeted therapies for cancer. The existence of cancer has been found to date back as far as two million years, in the form of evidence of lymphoma in a jawbone found in South East Asia by anthropologist, Louis Leakey (Mukherjee, 2010). As humans became aware of cancer, they sought to name and classify it.

The origin of current day terminology and labeling of cancer had its beginnings in ancient Greece. Mukherjee (2010) states, "It was in the time of Hippocrates, around 400 B.C., that a word for cancer first appeared in the medical literature: *karkinos*, from the Greek word for 'crab'." Sontag (1977) also discusses the term, *karkinos*, explaining that the term was used

because tumors and extending blood vessels were originally thought to resemble a crab, dug into the sand with its legs sticking out. Mukherjee (2010) also cites the historical use of the Greek word, *onkos*, which means load or burden, to describe tumors. This Greek term is the root word for the word, oncology.

The cause of cancer was first attributed to what Galen called "black bile" in 160 A.D., a time when the malady was treated by apothecaries with tinctures of lead or arsenic (Mukherjee, 2010). History shows that not much changed on the front of cancer treatment, until the 1760s. At this time, Scottish surgeon, John Hunter, began removing tumors from people in London (Mukherjee, 2010).

Surgery became the new norm in cancer treatment, until the beginnings of radiation oncology in the late 1800s. At this time, a medical student, Emil Grubbe, was inspired to use x-rays to treat local tumors in breast cancer patients after seeing the effects of x-rays on exposed factory workers, who experienced peeling skin and nails (Mukherjee, 2010).

According to Mukherjee (2010), the idea to use "curative substances" to treat cancer systemically, progressed with the advent of the microscope and the discovery that certain cells and tissue had affinity for certain dyes. This discovery led scientist Paul Erlich to re-think cancer treatment from a pharmacologic perspective. Further experimentation, coupled with the recorded effects of war-time exposure to mustard gas in 1943 on human bone marrow, kept scientists on this path (Mukherjee, 2010).

Mukherjee (2010) credits Sidney Farber as being the "Father of Chemotherapy," for his 1947 work with aminopterin as a chemotherapeutic agent to stop the growth of leukemia in children. Breakthroughs in chemotherapy progressed through the 20th century, along with similar breakthroughs in radiation oncology, which increased with each passing decade.

An outline of some other major cancer breakthroughs is included in Figure 1.

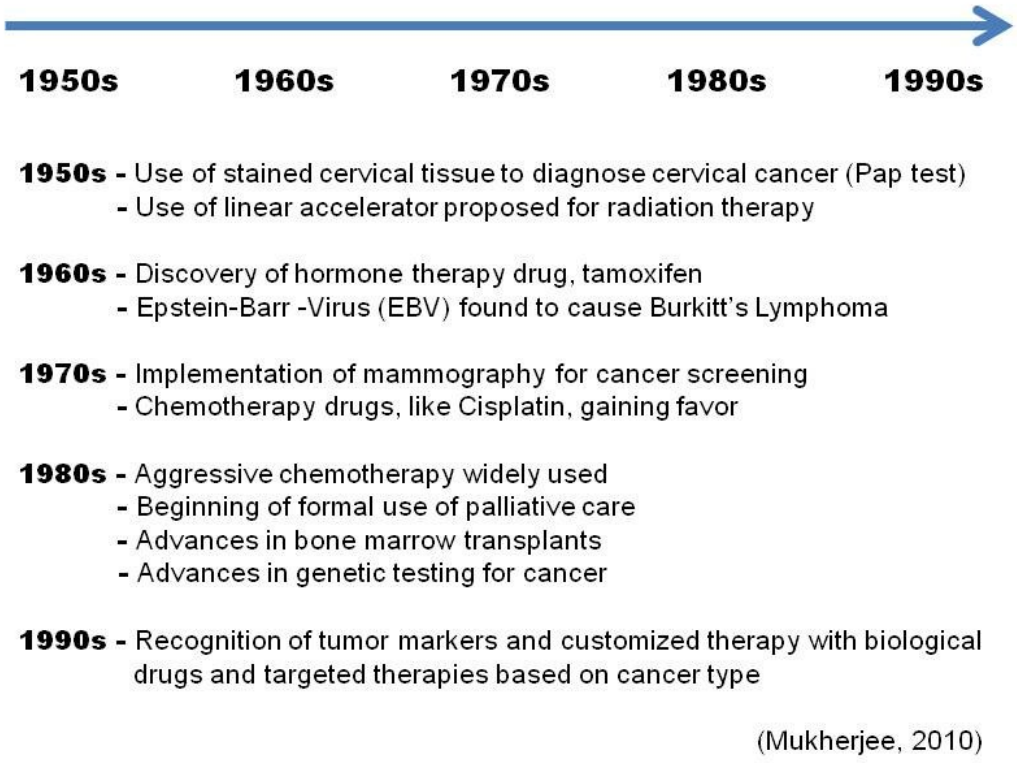


Figure 1: Cancer Breakthrough Timeline

Medical science has continued to seek out cures and treatments for cancer, because cancer has continued to afflict people. How medical science sees and treats cancer, is more than therapies; it also involves the role of healers and healthcare and differences in perception of the disease.

2.2. Medical Model of Patient Care

French philosopher, Michel Foucault reviewed the history of the medical profession and the "clinic," which in this case, refers to the teaching hospital (Foucault, 1994). One of the main points of Foucault's work is the regard (perspective) of the provider, which he calls the "medical gaze" (Foucault, 1994).

Foucault (1994) states that physicians needed to go beyond the medical gaze, which is organized and ordered by signs and symptoms, in favor of a "qualitative gaze," which includes the "subtle perception" of "qualities," "differences," and "variants." This perspective provides a more holistic view of disease within the patient, but still, only addresses the provider's perspective of illness.

Through the progression of the treatment from the bedside, to the clinic, Foucault (1994) recognized the transformation of the history of medical observation and disease models to include: knowledge of the patient, reorganization of the hospital, and the redefinition of the patient in society.

Foucault (1994) also refers to the "birth" of the clinic and the transition from 18th century health care to the 19th and 20th century models, as really not a birth at all, but a rediscovery or shift in the structure of knowledge. According to Foucault (1994), "…it was already there with the first forms of medicine…." As I see it, the shift in focus Foucault discusses, takes the medical perspective of disease from a focal point forward to a more systemic view of illness within a whole person, thus the use of Foucault's term, "qualitative gaze."

But, as we begin the 21st century, the view of the patient from the provider's perspective is still not as holistic as it needs to be. Godfield (as cited in Mukherjee, 2010) writes, "Cancer begins and ends with people. In the midst of scientific abstraction, it is sometimes possible to forget this one basic fact…Doctors treat diseases, but they also treat people, and this precondition of their professional existence sometimes pulls them in two directions at once."

Kleinman (1988) recognizes this problem, when dealing with the chronically ill, and suggests overturning the biomedical model, which focuses on disease only, for a biopsychosocial

model, which takes disease, psychological states, and even environmental solutions into consideration. This care perspective will be discussed further in the next section.

2.3. The Provider versus the Patient Perspective

Vance-Staiano (1979) addresses what Foucault (1994) called the "gaze," from a medical semiotic perspective, and notes that the interpretation of signs by providers in order to assign meaning to illness in the form of diagnosis as a disease or syndrome, is not without influence from cultural components. She also states that physicians and patients operate under their own codes for signs and illness. Semiotics and codes will be discussed in more detail under communication theory.

Kleinman (1988) addresses differences in provider and patient perspectives extensively, drawing a distinct difference between disease and illness, calling disease, *"*...the problem from the practitioner's perspective..." and sees it as being viewed as, "…an alteration in biological structure or functioning." Comparatively, Kleinman (1988) defines illness as "…the innately human experience of symptoms and suffering" and sees illness as, "…how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability."

Kleinman (1988) goes on to describes cancer, as follows: "Cancer forces us to confront our lack of control over our own and other's death. Cancer points up our failure to explain and master much in our world." Ucok's work (2007) mirrors Kleinman's (1988) observations, concerning a patient's sense of having lost control. Ucok (2007) focuses on the feelings of loss of control, created by surgical scarring related to cancer surgery and hair-loss caused by chemotherapy.

Kleinman (1988) recognizes that with the medical treatment of cancer, there is a disconnect between the patient's experience and the provider's perspective when he states: "The recording of a case in the medical record, a seemingly innocuous means of description, is in fact a profound, ritual act of transformation through which *illness* is made over into *disease*, *person* becomes *patient*, and *professional values* are transferred from the practitioner to the '*case*.'"

Donnelly (1995) also addresses the provider versus patient perspective of cancer. Donnelly states that the provider takes on an external perspective with focus on the etiology, diagnosis, and treatment of the disease, whereas the patient has a more internal perspective, which focuses on fear, pain, and death. Sontag (1977) supports this patient perspective of the disease when she states, "…in the popular imagination, cancer equals death."

The observation supports earlier research performed by Redlich (1945), where he showed that the words "cancer" and "tumor" evoked intense emotions of fear within his patient subjects. The research clearly shows that in a semiotic sense, the word "cancer" signifies different things to patients and providers.

In a clinical setting, the provider seeks to treat disease, while the patient experiences it. Though the provider can empathize with the patient's condition, he or she cannot fully understand the patient's experience and perceptions of fear and loss of control, unless, of course, he or she have experienced the disease first hand. Thompson (2009) states this concept as follows, "…it is as if the survivor and the clinician are singing from two different sheets of music without recognizing it." These issues become more significant when the extent of cancer in the human population is understood.

3. Significance and Relevance of the Problem and the Project

The significance and relevance of addressing communication gaps and perception differences in oncology is best emphasized by the number of people in the United States who are diagnosed with cancer each year. The American Cancer Society (ACS) puts the estimated number of new cases of cancer in the United States for 2012 at more than 1.6 million (2012). Though there are more than 100 kinds of cancer, the most common types to be diagnosed include prostate, breast, lung and bronchus, colorectal, and melanoma (a type of skin cancer) (ACS, 2012). The ACS statistics for the most common types of cancer diagnosed alone, total 914,480, and are broken down in Table 1.

Table 1: Estimated Number of Cancer Cases for 2012 by Type
(from the American Cancer Society publication, *Cancer Facts & Figures 2012)*

Type of Cancer	Number of Cases in 2012
Prostate	241,740
Breast	226,870
Lung and Bronchi	226,160
Colorectal	143,460
Melanoma (A type of skin cancer)	76,250

According to the ACS (2012), the lifetime risk of a person developing cancer is approximately 1:2 for women and 1:3 for men. Risk also increases with age, and 77% of all cancers are diagnosed in people age 55 and older (ACS, 2012). The number of people being diagnosed with cancer each year points to the need for affective patient information documents concerning this disease.

Thompson (2009) discusses the importance of bridging this communication gap, stating, "Eliciting and discussing these differences allows for collaboration on areas of disagreement between the biomedical model and the lay model, thus minimizing non-compliance and increasing information exchange." Thompson's biomedical model and lay model parallel the provider versus patient perspective model I refer to in this paper.

Not only does a patient information document customized to a patient's experience serve in filling the informational communication gaps and in easing the patient's perspective of psychological suffering, it also alleviates the provider's role as sole educator in emotionally charged situations within a large patient population.

Thompson (2009) addresses the emotional side of cancer when she notes that a cancer diagnosis can serve as an "emotional emergency" to the patient, and, that at the time of cancer diagnosis patients are struggling to manage fear. One patient with breast cancer, whom Thompson interviewed, described the situation as follows: "You are trying to give me medical information and I'm worried about whether or not I'm going to live to see my daughter graduate" (Thompson (2009).

Kleinman (1988) emphasizes the delicacies of presenting medical information addressing the role of the physician in the task, when he states, "Presenting the biomedical model to the patient is an act of translation for the practitioner. When the translation is well done, the physician has the great advantage of collaborating with accurately informed patients and families who can contribute to the therapeutic process. When it is poorly done, however, the stage is set for clinical communication to have serious problems, which can unsettle the therapeutic relationship and thereby, undermine care."

This communication problem becomes more critical, when results of a study by Longo et

al. (2009) are considered. Longo et al. (2009) reported that communication with doctors and other health professionals were a primary information source for breast cancer patients, with 91% seeking information from physicians and 71% percent seeking information from nurses. These percentages serve to emphasize the importance of communication between providers and patients.

Kleinman (1988) recognizes the value of educational material in the provider-patient relationship, when he states, "Videotapes and written material can be prepared specifically for this purpose. The act of formerly training patients and their families as care givers is a message of empowerment that is symbolic as well as practical significance. Viewing the patient as a colleague and therapy as collaboration would, I believe, greatly improve the quality of the patient-doctor relationship." I agree.

Some sort of educational material, which is given to patients in addition to discussion with the provider, serves to reinforce information and provide a safety net for those patients who are just too stunned to absorb anything that has been said to them after hearing the words, "You have cancer."

More recent studies confirm that the use of information does alter the patient's experience, and emotional and psychological states for the better. Chelf et. al. (2001) analyzed 176 different studies on cancer-related patient education and reported that patients with cancer benefit from detailed information, with the majority reporting that they desired receiving the maximum amount of information about their disease. Rawl et. al. (2002) found that a computer-based, nursing intervention program significantly reduced both anxiety and depression in cancer patients.

In a study conducted at the Mayo Clinic in Rochester, Minnesota, Deshler et al. (2006)

showed that a cancer orientation program, which included a video and companion booklet, not only contributed to higher patient satisfaction, but also lowered a patient's anxiety levels in some cases. Patient anxiety was assessed using Profile of Mood States (POMS) and Spielberger's Trait Anxiety Inventory (STAI).

4. Communication Theory: The Science Behind the Solution

In order to be effective at solving the communication gaps and perception differences, the production of a patient information document must be grounded in evidence-based communication theory and applications. I have focused on applicable communication theory, the use of plain and objective language, accepted document design principles, and other supporting evidence for choices to complete this task.

4.1. Communication Theory

McLuhan (1967) coined the phrase "the medium is the message" with the belief that the medium used to transmit a message affects how the audience perceives it. This phrase is especially true with patient information documents, which deal with health and wellbeing. The perception of the document through the medium is extended to both the science of medicine and the facility providing health care. Care must be taken to provide accurate and trustworthy information to instill faith and trust in the reader's perception of his or her care and treatment.

With this relationship understood, the patient information document serves as a form of health information rhetoric, presenting information about Western medicine's perceptions and treatments of disease. Therefore, it is helpful to view the document from a rhetorical perspective, as well as an educational and informational one.

The early Greeks defined the five canons of rhetoric as applied to speaking. They include: *invention*, which is the determination of topics and supporting material; *arrangement*, which addresses the structure of speech; *style*, which is the use of language to create a desired effect on the audience; *delivery*, which is the presentation of a speech; and *memory*, which is

remembering what to say (Borchers, 2006). The first four of these canons can be applied to the written rhetoric of the patient information document.

Invention includes the process of collecting and collating information for the document, with special attention paid to proof, which is persuading the audience that the information is valid. This canon includes the use of Aristotle's artistic proofs: *ethos, pathos* and *logos* (Borchers, 2006). *Ethos* is the character of the speaker (Kimball and Hawkins, 2008). If the media is to be the message, it is important the patient information document reflect on the character of the health care facility it represents. Aristotle also addresses *pathos*, which is an appeal to emotion (Kimball and Hawkins, 2008). The speaker (in this case, the writer) must take into consideration the audience's (patient's) emotions. This strategy is accomplished by the acknowledging the emotions concerning fear and loss of control (Kleinman, 1988) experienced by patients, and the invention of a document that presents information with these issues in mind. *Logos* refers to reasoning, which relates to the material in the patient information document, which , in turn, relates to the use of standard Western medicine involved with cancer care.

Arrangement entails the structure or order of the speech or document, which is necessary for effective communication (Borchers, 2006). Organization in a patient information document is critical in presenting information in a logical fashion, where it is easy to find and access information as wanted and/or needed.

Style, which Aristotle defined as "to be clear" (Borchers, 2006), was broken down according to complexity of speech in categories, including grand, middle, and simple. For the purpose of a patient information document designed to help bridge communication gaps concerning language, using simple speech is clearly the style of choice. I incorporated this

canon in the patient information document through the use of plain language (NIH, 2010), which will be outlined in further detail in the next section.

Delivery in speech is applied to voice quality and physical movement (Borchers, 2006). With printed rhetoric, the delivery falls in the printed word, layout, and design of the document. This canon will be discussed further, under document design principles, but basically, what is seen and read clearly influences the audience regarding their perceptions of information received.

Charles Sanders Pierce and Ferdinand de Saussure are regarded as the co-founders of semiotics, which deals with signs and their meaning. Pierce is quoted as stating: "A sign is an object which stands for another to some mind," (as cited by Hoopes, 1991). Pierce also states, "Our ideas have also a causal relationship with the things they represent without which there would be no knowledge," (as cited by Hoopes, 1991). Pierce's and Saussure's theories can be applied to the differences in perspective between patients and providers in oncology. The knowledge of the patient and the knowledge of the provider are different based on the causal relationships and conventions they represent to each party.

Saussure (as cited in Chandler, 2002) constructed a dyadic (two part) theory of semiotics, where:

- the sign vehicle was called a *signifier*
- the meaning of that sign was called the *signified*.

Pierce (as cited in Chandler, 2002) explains the concept with a triadic (three part) model where he labeled:

- the form the sign takes, the *representamen*
- the sense made out of the sign, the *interpretant*

- something beyond the sign, which it refers to, the object or *referant.*

With cancer, the *signifier/representamen* (the form the sign takes) is in the discovery of a tumor or presence of cancerous cells as seen under the microscope. The *signified/interpretant* (the sense made out of the sign) and the object or *referant* (representation of something beyond the sign), however, depend on the perspective of the patient and the provider.

For the provider, the *signified/interpretant*, takes on a focus on the etiology, diagnosis, and treatment of the disease. For the patient, the perspective is shifted to fear, pain, and death (Donnelly, 1995).

Going on to Pierce's triadic model (as cited in Chandler, 2002), the object or *referant* (representation of something beyond the sign), would also be different depending on the provider's and patient's perspective. As I see it, the provider would see the *referant* as the need to develop and implement a treatment plan for the patient. The patient would see the *referant* to be the physical and emotional challenges associated with the illness and the treatment that the provider is laying out for him or her.

Pierce (as cited in Chandler, 2002) goes on to further classify signs as being either *iconic*, *indexical*, or *symbolic*. *Iconic* signs closely resemble what they represent, *indexical* signs obtain their meaning from associations they have with another object, and *symbolic* signs are based on convention and agreement of what they mean (Chandler, 2002). Medical symptoms are examples of *indexical* signs. The tumor or cancerous cells have been given an association to the disease called cancer. The language of oncology is more *symbolic.*

Language serves as a code system that helps people make sense out of symbols in the form of words. Umberto Eco defined codes as "a system of rules given by cultures (as cited in Borchers, 2006). The words used in cancer care and in normal language each have their own

meanings based on cultural codes. Though the provider and the patient may share in a general cultural language codes as people living within a given country or community, providers also belong to a subculture dealing with the practice of Western medicine and its own language codes.

Chandler (2002) states: "The conventions of codes represent a social dimension in semiotics: a code is a set of practices familiar to users of the medium operating within a broad cultural framework." This statement is supported by Borchers (2006), who exemplifies this belief with the statement: "When words mean different things to different people or when a word can have several meanings, codes do not help us make sense of the signs we encounter." This theory clearly applies to the patient's perspective in cancer care and supports the need for a patient information document to help bridge informational and perception gaps.

Richard Weaver recognized the power of association we place on images and symbols in the early 1950s, when he validated the power certain words can have to be positive or negative, when he coined the phrases "God terms" and "devil terms" (as cited by Borchers, 2006). For many patients and cultures, cancer would be classified as a "devil term" and be considered evil.

Vance-Staiano (1979) also discusses how signs are often seen as judgments or moral statements involving the individual and those who surround him or her. According to Vance-Staiano (1979), "…the evaluative aspect of signs is of considerable sociological importance."

Semiotics not only explains differences between patient and providers perceptions, but it must play a role in the choice of words and images within a patient information document as a means of communicating. Content within the patient information document must be created with these perceptions, when considering layout, color, type and font, and image. All these elements serve as signs to the patient with interpreted meanings that communicate information based on

cultural codes and a patient's perceptions. The use if signs in the patient information document will be explored in more detail later in the paper.

Rhetoricians dating back to Aristotle have recognized and accepted that the communication process involved human's perception of input. In the twentieth century, the Shannon-Weaver Mathematical Model (Heimann, 2006) describes communication as a signal between a sender and receiver. Shannon designated interference in the message as "noise." In the patient-provider model, the provider is the "sender", the patient is the "receiver," and the "noise" is the medical terminology language barrier, coupled with the discrepancies between the provider's clinical perspective versus the patient's emotional one. See Figure 2.

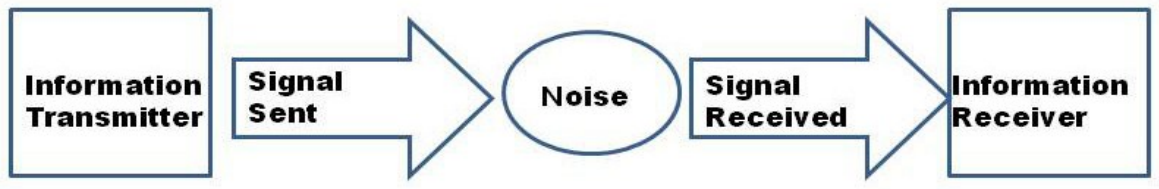


Figure 2: Shannon Weaver Model Applied to Cancer Communication (Heimann, 2006)
The provider is the transmitter. The noise is the differences in knowledge and perception, which clouds the message received by the patient, who is the information receiver, in this case.

4.2. Use of Objective and Plain, Language

The choice of words and their presentation are critical in the production of the patient information document designed to bridge communication gaps. Objectivity and plain language are both considered.

4.2.1. Objectivity

Sontag (1977) is quick to point out that illness is *not* a metaphor. She goes on to state, "…the most truthful way of regarding illness—and the healthiest way of being ill—is one most

purified of, most resistant to, metaphoric thinking." Sontag notes the historical use of metaphor in both tuberculosis and cancer and the many negative connotations related to these diseases as a result of the use of metaphor.

Sontag (1988) also addressed metaphor with the case of Acquired Immune Deficiency Syndrome (AIDS), where she gives Aristotle's definition of metaphor from *Poetics,* as the "…giving the thing a name that belongs to something else." The naming creates perceptions that can create negative social stigmas in relationship to disease.

Sontag (1977) states, "It is not naming as such that is pejorative or damning, but the name 'cancer.' As long as a particular disease is treated as an evil, invincible predator, not just a disease, most people with cancer will indeed be demoralized by learning what disease they have."

This perception extends to the patient from those on the outside, as indicated in Sontag's (1977) observation, "Any disease that is treated as a mystery and acutely enough feared will be felt to be morally, if not literally, contagious. Thus, a surprisingly large number of people with cancer find themselves being shunned by relatives and friends and are the object of practices of decontamination by members of their household, as if cancer, like TB, were an infectious disease."

Applying Sontag's observations to the emotional issues patients face concerning fear and loss of control, confirms that it would be in the patient's best interest to omit any reference to negative metaphor concerning cancer in the production of the patient information document. This avoidance of metaphor is done in the interest of objectivity, and what Sontag (1977) calls, "the most truthful way of regarding illness." This choice also allows patients to construct or

embrace their own metaphors for cancer, or not, based on their own experience and comfort level.

It should also be noted, that just as Sontag (1977) referred to patients as "people with cancer" as opposed to "cancer patients," I have used this more passive connotation in my patient information document. This terminology ensures that the person is put before the disease and avoids defining people by the very disease, which inspires fear and anxiety within them.

Thompson (2009) makes another argument for objectivity, when comparing lay explanatory models as compared to biomedical explanatory models, when she recognizes problematic divides between patients and providers concerning mortality, context of illness beliefs about etiology, and demotion of shame, blame, and fear. Thompson (2009) states that patients need to weave together an explanation of their disease, based on past and current experiences which are often rooted in emotion. Removing causality through objectivity, free from metaphors, can help ease the shame, blame, and fear, which Thompson discusses. It is also important that in this process of maintaining objectivity, the patient can still understand what is being said.

4.2.2. Plain Language

The ancient Greeks understood the applications of different levels of language and when it is best to speak simply. Next to objectivity, in order for the document to be affective, the medical and technical material must be presented in such a way that people can better understand what is being said to them. Doak (as cited in Aldridge, 2004) states that adults generally prefer easy-to-read material over material that is more challenging to read. Chelf (2001) agrees, but notes, however, that accomplishing this task with cancer-related information is a challenge, when

she states: "Easy-to-read materials do not always have the same level of detail as those written at a higher level and may not resolve a knowledge gap."

In October of 2010, President Barack Obama signed the Plain Writing Act of 2010 (H.R. 946/Public Law 111-274) (NIH, 2010), requiring that the federal government write documents in simple easy-to-understand language. The National Institutes of Health (NIH) adopted and fully supports the use of plain language and defines it on their Web site as: "Writing that is clear and to the point helps improve communication and takes less time to read and understand. Clear writing tells the reader exactly what they need to know without using unnecessary words and expressions," (NIH, 2010).

The NIH (2010) goes on to address the importance of communication with health-related material through its Plain Language Initiative: "It (plain language) also improves reader response to messages. Using plain language avoids creating barriers that set us apart from the people with whom we are communicating." The institution recognizes that health literacy involves a number of abilities, beyond reading and comprehension, including: analyzing information, and decoding instructions, symbols, charts, and diagrams. Plain language is used to assist patients in making health care decisions and taking action. The NIH (2010) recommends the use of clear writing with common everyday words, except for necessary technical terms, whenever possible. Under clear writing, the NIH initiative also recommends:

- Using personal pronouns, such as "you"
- Using positive, rather than negative words
- Using present tense
- Using parallel sentence construction
- Using active voice

- Knowing the target audience, their needs, and their literacy levels
- Using short sentences and paragraphs
- Using strong, logical organization in sentence and paragraph structure
- Using a table of contents to help the reader understand how the document is organized
- Considering document layout to include margins, headings and white space
- Using tables and figures to help make complex information readily understandable
- Using typography for emphasis, including fonts, bullets, and italics

Aldridge (2004) also suggests strategies for creating patient information documents, such as using typography for emphasis, using of a limited number of fonts, placing of critical information in prominent spots, repeating critical information, using graphics and pictures to help explain concepts, and using white space.

In producing the patient information document, I have incorporated suggestions from NIH (2010) and Aldridge (2004) as a guideline. I have, however, made some exceptions, including the use of passive voice at times in the document in order to interject some objectivity.

The Online Writing Lab at Purdue University (OWL, 2012) states that with scientific writing, passive voice is more readily accepted. This exception helps to create a more objective, fact-based presentation of information. Medical material related to cancer is extremely scientific, and the science behind oncology is the basis for cancer treatments. More notable, the objectivity of passive voice can serve to change perspective.

For example, my choice of words describing cell division in the patient information document can be interpreted different ways, depending on the voice used. The more passive

choice of, "The genetic material is copied and redistributed in a process called cell division," which I used, differs from an active version, "The cell copies its genetic material." The former takes into consideration the patient's perspective. The latter conjures the thought of a cell actively copying its genetic material and takes on Sontag's (1977) perception of cancer as "an evil, invincible predator." The passive description I have chosen makes the act of cell division less threatening and more objective, and it reduces risk of the application of negative metaphor and the related fear and loss of control that accompanies it.

The choice of words and their order can clearly change perception, as does document design.

4.3. **Document Design**

Document design is a science in itself. In the case of a patient information document, document design is also information design. Here, large amounts of complex information are made clear and accessible to audiences to create, what Kimball and Hawkins (2008) call "…a visual system of meaning." Kimball and Hawkins (2008) also address the need to consider a multilevel approach to information design appealing to: the *physical* level (visual and physical elements of the document), the *cognitive* level (structure and presentation of information in regard to problem solving), and the *affective* level (ability of the document to gain attention and inspire action).

The overall goal of a patient information document, which informs and bridges communication gaps, is to convey meaning and create relationships through its features, including content, structure, and orientation, while meeting the user's needs (Kimball and Hawkins, 2008).

From the choice of medium to organization of content and everything in between, there are best and recommended practices and communication science behind the production and publication of information. These include color choices, font, choice of images, signs, and symbols.

4.3.1. Medium of Choice

When choosing a medium, document designers need to take into consideration convention, which is what the user's experience is concerning similar documents, and other human factors, such as the physical qualities of the document and ease of use (Kimball and Hawkins, 2008).

There is a wealth of knowledge available to cancer patients on the topic of cancer care available through printed resources, web sites, and video. However, patients are still left to wade through the information and find appropriate subject matter and topics at a time when they are compromised psychologically and physically.

The emotional challenges of facing a life-threatening illness, coupled with the physical side effects of treatments, such as chemotherapy and radiation, can make it difficult for a patient to find and assimilate information concerning relevance and objectivity. This limitation must be considered when choosing the best, most affective medium to transmit the message to the patient.

A study by Longo et al. (2009) reported on use of information media for 158 patients with breast cancer. Results showed that 91% of patients sought information from their physicians, with 76% using that information to make health care decisions.

The use of Web sites was also reviewed. Longo et al. (2009) reported that the two most recognizable Web sites, as identified by study participants, were those of the American Cancer

Society (ACS) and the National Cancer Institute (NCI). Though recognition ranked high for both sites, the actual number of participants who had actively sought information from those sites, differed sharply. The figures listed in Table 2 show that knowledge of a Web site's existence did not guarantee use.

Table 2: Differences in Resource Recognition and Use in Breast Cancer Patients (*Longo et al.,2009)*

Resource	Percent Recognized (%)	Percent Used (%)
American Cancer Society Web site	93	46
National Cancer Institute Web site	85	34

The numbers were much more promising for printed media. Longo et al. (2009) reported that 96% of patients were aware of books, with 72% using them. Magazines were also a source of information. Longo et al. reported that 77% of participants were aware of magazines with cancer information, and 99% of those who used them applied the information to their personal health issues, with 51% using the information to make healthcare decisions. These figures support that both providers and printed media, especially books and magazines, were sought after resources for cancer information by breast cancer patients. Given this information, producing a patient information document in a printed format, has its merits.

Another argument for using a printed resource comes from cancer statistics and usability data for online resources with senior citizens. With 77% of all cancers diagnosed in people age 55 and over (ACS, 2012), the target population or audience for the patient information document is primarily adults, age 55 and older.

According to the Nielsen Norman Group (2002), a Web usability study of senior citizens, age 65 and older, showed that "current Web sites are twice as hard to use for seniors, as they are

for younger users." The report also noted that for most seniors, email was the primary Web application used, though other uses included: general research, news, investment tracking, health related research, and a smaller number, who did shopping or banking online (Nielsen, 2002).

A noted problem included the success of those using the Web. According to Nielsen (2002), a usability study assessing fact-finding, online purchasing, retrieving information, and comparing and contrasting, seniors had a lower success rate for completing a task correctly on line. See Table 3.

Table 3: Success Rates by Age in Online Tasks (Nielsen, 2002)

Assessment	Seniors (Age 65+) (%)	Control Group (Age 21-55) (%)
Success Rate (Task completed correctly)	52.9	78.2

In the last decade, the senior citizen demographic group has continued to show growth in their use of the Web. According to Raine (2012), more than half of seniors use the Web, and 58% of these online users have sought medical and health related information on the Web. These findings and statistics are promising for the future reliance on the Web for patient information, but currently there are a significant number of older citizens who are not using the Web for health information. And, as Table 3 indicates, there is still concern about how successful the older population is in using a Web resource. The data clearly supports the need for a patient information document in printed form.

With the decision for a printed medium made and supported, the next phase of the project was document design.

4.3.2. Design Practices

Design practices are based on basic design principles. Kimball and Hawkins (2008) outline six basic principles of document design to include *similarity*, *alignment*, *contrast*, *proximity, order*, and *enclosure*. Williams (2008) also includes *repetition* as an important design principle. I have used all these principles in the production of the patient information document and will discuss the principles and their use below.

Similarity entails using elements that are alike in appearance or function. The document shows consistent use and placement of type and font, color, and images on the page. Sections are divided by topic and consistently separated by tabbed pages with similar design.

Alignment creates a sense of connection and coherence. Text and images are aligned consistently throughout the document.

Contrast is used to show differences and create emphasis. The document uses bolded, hierarchical headings in *sans serif* type in contrast to the use of *serif* type for text. Images and figures also provide contrast to the text.

Proximity is used to show grouping or relationship. Information in the document is grouped by topic and kept together, as are relevant tables and figures.

Order is the presentation of information in sequence and/or by importance. This principle is exemplified with the table of contents, tabbed sections, and headings included in the document.

Enclosure is used to show separation. This principle is utilized throughout the document with the use of boxes and lines in tables, and the use of negative or white space around text, figures, and images set within the text.

Repetition (Williams, 2008), the repeating of elements throughout a document, is seen in the use of consistent, unified use of color, shape, font, and format. Question mark and compass icons also are present throughout the document, creating sense of continuity.

It should also be noted that the principles of *proximity* and *similarity* relate to natural tendencies outlined by Gestalt theorists regarding the grouping of figures, while the principle of *enclosure* relates to the Gestalt theory of common region (Kimball and Hawkins, 2008).

Principles of design are based on visual communication theory and Kimball and Hawkins (2008) outline visual communication into the categories of *visual perception*, *visual culture*, and *visual rhetoric*.

Visual perception is biologically and psychologically based. It involves the neuropsychology of how color is perceived by humans through the sensory interpretation of light and wavelengths and how they are interpreted.

Visual culture is based on perception of visual cues, which are based on cultural perceptions and conventions and is semiotic in nature.

Visual rhetoric involves how communication is used to influence others. This entails *ethos* and *pathos,* which was previously discussed under communication theory. Design is a vehicle for communication and includes the need for visual choices that support the message that is being communicated.

4.3.3. Color Choices

Mahnke (1996) discusses evidence of how human beings react to color and light and how this knowledge is used to influence physical environment. According to Mahnke (1996), color is, "…the sensation caused by certain qualities of light that the eye recognizes and the brain interprets." Though Mahnke's work is primarily with environment and architecture, the

principles apply to print production, when we view the printed document as a microcosm of the user's external environment.

Mahnke (1996) states that humans are influenced by color at conscious, subconscious, and unconscious levels and that they react to color and light on both a psychological and physiological level. These factors contribute to the linking of emotion and physical well being to different colors. Mahnke (1996) also cites relationships and correlations between color and cortical activation in the brain, functioning of the autonomic nervous system, and hormonal activity within the body. He uses a color experience pyramid to demonstrate the complexity of human relationship to color. See Figure 3.

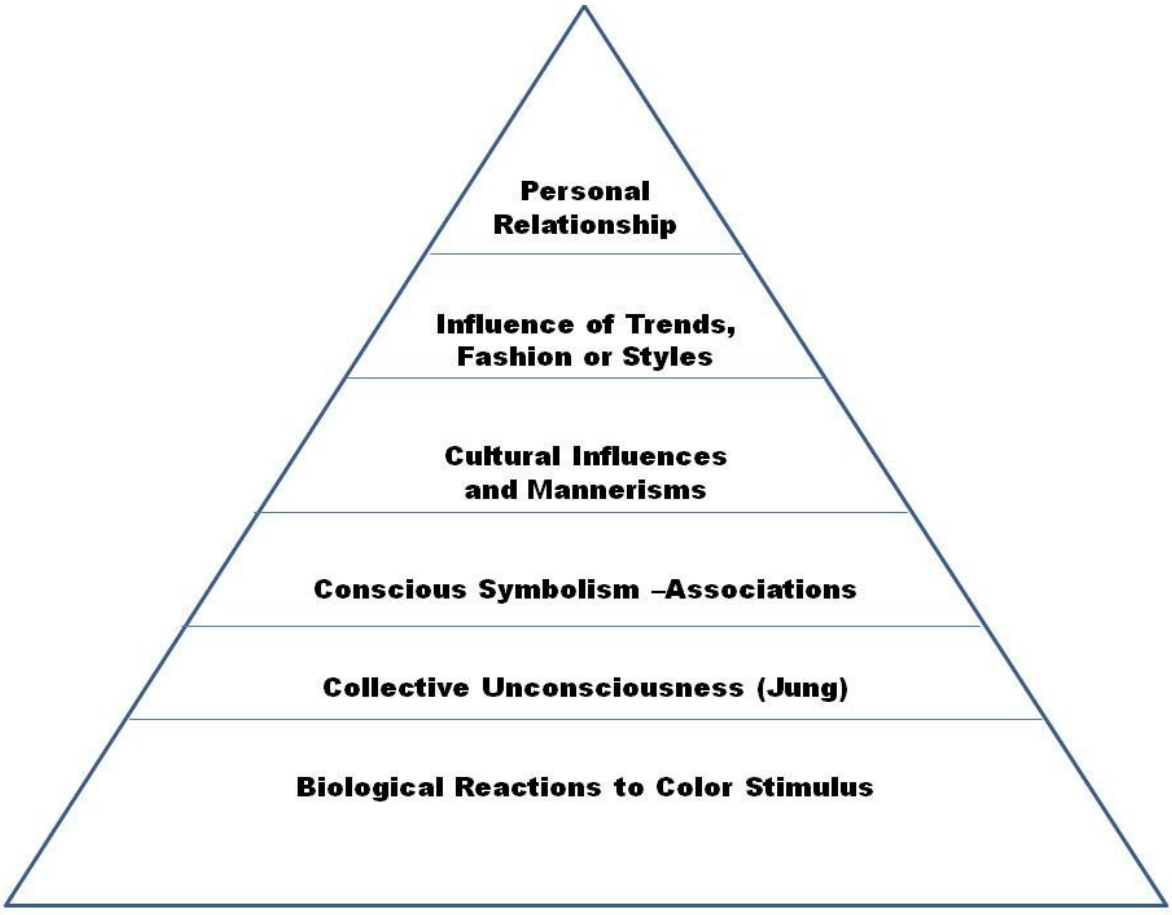


Figure 3: Mahnke's Color Experience Triangle

The triangle is an ascending hierarchy, beginning at the base, with the basic biological ability to distinguish and respond to color at physical and psychological levels.

In the second level, Mahnke refers to the Jungian concept of the collective unconscious as archetypes, which are the fundamental images formed in human development and are part of our psyche that is independent of conscious or unconscious reactions (Mahnke, 1996).

In the third level, Mahnke (1996) moves to the level of conscious symbolism-associations which are learned responses made up of impressions and symbolism that we react to on a conscious level.

The fourth level addresses cultural influences and mannerisms. These reactions can be specific to cultures and groups or regions, but many are universal and cross cultural boundaries (Mahnke, 1996).

The fifth level concerns the influence of trends, fashions and styles, which are used primarily in consumerism and fluctuate historically due to boredom and desire for change (Mahnke, 1996).

The last level relies on a personal relationship to color, which is influenced by all the lower levels.

The concepts of the color reaction to specific colors are widely used in marketing (Eiseman, 2006) and are critical in choosing a color scheme for a patient information document that has emotional components related to the content. Where patients with cancer face fear of death and anxiety from loss of control, colors used in the document can be chosen to counter those feelings (*pathos*), as well as to instill a sense of credibility to the document (*ethos*), further minimizing their distress.

The choice of color for the patient information document took into account perception of colors and color schemes based on emotional response to color. The colors and associated meanings are outlined in Table 4.

With emotional responses to all colors noted, I chose colors with positive, hopeful and calming attributes, to counter feelings of fear and anxiety documented in cancer patients (Donnelly, 1995).

Table 4: Emotional Associations and Response to Color

Color	Response (Mahnke, 1996)	Response (Eiseman, 2006)
Blue	Considered the peacemaker color, blue has positive connotations of calmness, security, comfort, sobriety, and contemplation.	Blue brings a sense of quiet, calmness, serenity, respite, introspection, and coolness. It also indicates dependability and loyalty.
Green	Considered relaxing, green has positive connotations of being tranquil, refreshing, quiet, natural and restful to the eye.	Green symbolizes nature and new beginnings, along with youth, survival, and health. It is considered calming.
Yellow	Considered reflective, happy, and luminous, yellow has positive connotations of being cheerful, high spirited, and suggestive of the life-giving sun, which represents a bright future, hope, and wisdom.	Yellow brings a sense of joy, hope and optimism and is associated with heat, light, vitality, energy, curiosity, and enlightenment.

Blue, green and yellow naturally fall into an analogous color scheme, adjacent to one another on the color wheel (Williams, 2008). See Figure 4. The colors are also preferable to other color choices, when emotional response is considered.

For example, according to Mahnke (1996):

- Red can be arousing, exciting and stimulating
- Orange, although it can be cheering, can also be exciting and stimulating
- Purple is considered a conflicted color, taking in aspects of red and blue, two colors that are oppositional. The color can take positive connotations of being royal, dignified or exclusive, along with negative associations of being lonely, mournful, and pompous.

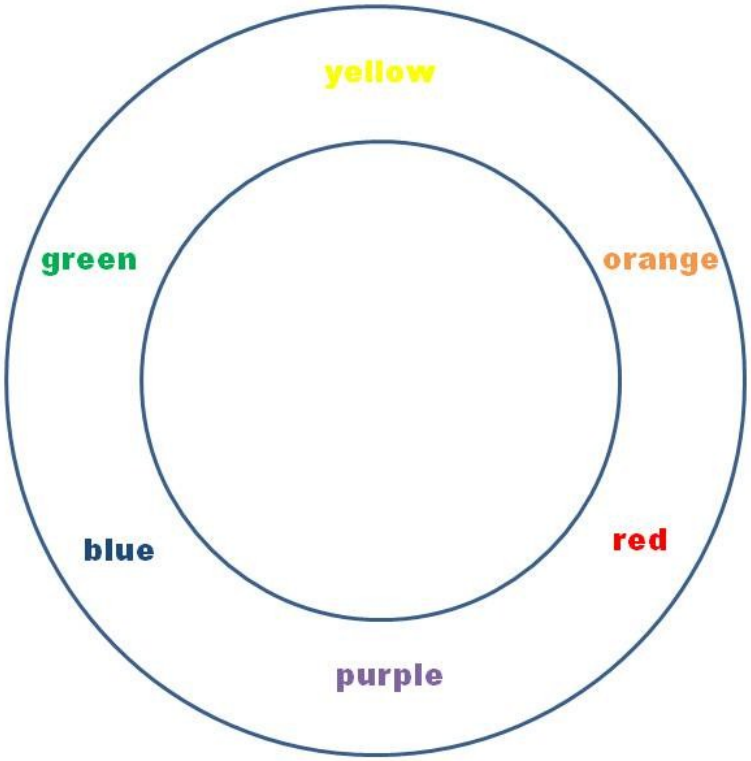


Figure 4: Basic Color Wheel

As with color, font choice in the document can also send messages to the reader.

4.3.4. Typeface and Font Size

When choosing the typeface and font size, it is important to take into account the perception of that choice in terms of cultural and rhetorical interpretations, as well as the legibility and readability of the type.

In regard to typography, culture and rhetoric determine the tone or *ethos* of the message (Kimball and Hawkins, 2008). Typeface is associated with "personality" or tone (Mackiewicz and Moeller, 2004) and considered a type of visual rhetoric (Brumberger, 2003). Shriver (as cited in Brumberger, 2003) addresses the rhetorical appropriateness of typeface choice, concerning "…the purpose of the document, its genre, the situation, and the audience's needs, desires, and purposes."

A study by Mackiewicz's and Moeller's (2004) showed that study participants rated different typefaces according to personality attributes, with designations of being friendly, professional, technical, formal, elegant, and artistic, dramatic, and individual. It should be noted that Brumberger's (2003) study of typeface perception showed a direct correlation between cultural ideas of appropriateness of type in different settings, though the study failed to prove a statistically significant effect in typeface changing the interpretations of text persona. See Table 5.

With medical information, the choice of a typeface should represent professionalism and a serious tone. Serif type, such as Times New Roman, the type the body of this paper is written in, is considered easier for the brain to recognize and best used for the body of the document (Kimball and Hawkins, 2008).

Table 5: Typeface Personality

Typeface Example	Personality Attributes (Brumberger, 2003)	Personality Attributes (Mackiewicz/Moeller, 2004)
Times New Roman	Serious	Professional, Formal
Arial*	Appropriate, Professional	Technical

**** Akin to Helvitica in the Mackiewicz/Moeller study***

Headings in patient information documents must also take into consideration the tone and *ethos* of the message and a conservative choice suggesting professionalism is best, for the reasons stated above. The use of a sans serif type to contrast the body of the text is a common design practice.

My choice of typeface for the patient information document headings and text body are supported by these studies and included Times New Roman for the text body and **Arial Black** for the headings.

I have also included a non-medical quote and a cancer-related poem in the document to counter emotional issues faced by patients with cancer. For these elements, I chose the typeface, Papyrus. Unlike other script-like typefaces available, this typeface is relatively easy to read, while adding contrast and a change in tone. Though not directly evaluated, both Brumberger (2003) and Mackiewicz and Moeller (2004) give attributes to script and script-like typeface, such as Papyrus. These included perceptions of script as being elegant, friendly, artistic, and dramatic. The change in tone of the type indicates that the material in the document in this typeface is delivering a different kind of message, in contrast to the other typefaces used. I believe this choice is more suitable to the non-medical messages in the document.

The Centers for Disease Control and Prevention (CDC) recommends using font sizes between 12 and 14 points (CDC, 2009) in health-related material. This recommendation is confirmed by Aldridge (2004) who suggests using at least a 14 point font size. With a target

population for cancer made up of 77 percent of patients over the age of 55 (ACS, 2012), I felt it best to go large for body text and chose a Times New Roman 14 point font. Since font sizes appear differently, as shown by their use in this section, the heading choice of **Arial Black** was acceptable at **10 points**, **12 points**, **14 points**, and **16 points** for ease of reading.

Legibility and readability are also important when reading is looked at as a visual activity. According to Kimball and Hawkins (2008), the shape of letters comes into play as they are grouped to signify phonetic sounds that combine into words with their own distinctive shapes called *boumas*. As previously stated, serif type, such as Times New Roman, is considered easier for the brain to recognize and best used for the body of the document (Kimball and Hawkins, 2008). Use of *sans* serif fonts for headings is easy to read in short phrases.

4.3.5. Images, Signs and Symbols

Semiotics teaches us the importance of choosing images in communication, as they serve as signs, symbols, and vehicles for conveying meaning. The CDC (2009) recommends the use of photographs and simple illustrations or line drawings in the productions of informational material. The CDC (2009) also states that "photographs work best for showing 'real life' events, people and emotions," while simple illustrations work best for simplifying complex ideas. I have used both medial and non-medical photographs, along with illustrated figures within the patient information document to communicate ideas and concepts. I will begin by discussing medical images.

4.3.5.1. Medically Related Images

Medically-related examples of a photograph and an illustration following CDC (2009) guidelines, which were used in the patient information document, are shown in Figure 5. The guidelines suggest:

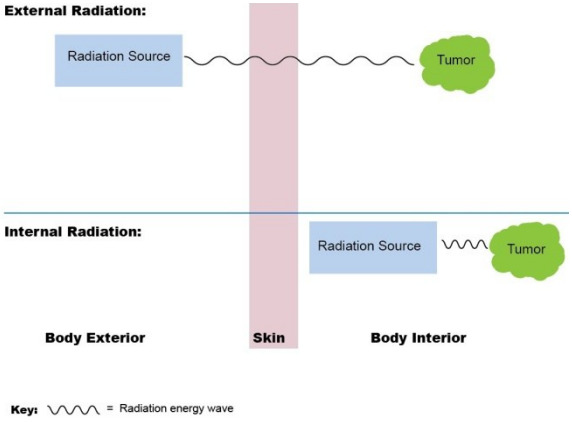
- Presenting one message per visual image
- Keeping images easy for the audience to follow and understand
- Using captions as a narrative to the image
- Using high quality photographic images to make the message more credible

An example of a visual image used in the patient information document is *Example 1: Figure 4*, shown in Figure 5. Though the photo collage is composed of several images, it still portrays one message, which is "types of cancer treatment."

With the above guidelines in mind, I selected and purchased the majority of medical photographs used in the patient information document from Shutterstock.com. Other photos were collected, following the same guidelines, from various sources found at Google Images and referenced, accordingly. I designed and created diagrams included in the document using Adobe Illustrator, following CDC recommendations.

In the act of choosing medically-related photos mentioned above, I also referred to the study of visual social semiotics, which focuses on how images convey meanings (Harrison, 2003). Harrison (2003) compares image composition to the syntax of a sentence and how components of images, such as content, relationships, angle, and perspective affect how viewers interpret people, places, and objects within images.

Example 1: **Figure 4: Treating Cancer**
Cancer is treated in a variety of ways. The most common treatments include surgery, top left, chemotherapy, top right, and radiation therapy, bottom left. Other therapies, include biological therapy, hormone therapy and targeted therapy. (Photos from Shutterstock.com.)



Example 2: **Figure 7: External versus Internal Radiation Therapy**
Radiation in the form of energy waves can be given externally or internally.

Figure 5: Examples of a Medical Photograph and Figure from the Project
Photographs work best for showing actual events, people and emotions, while simple illustrations work best for simplifying complex ideas.

Harrison (2003) discusses the importance of using images in technical communication, because readers do not rely only on the written word for comprehension. Harrison (2003) states that images perform three meta-semiotic tasks to create meaning: *representational meta-function*, *interpersonal meta-function*, and *compositional meta-function.* I will address each meta-function and have included an exemplary photograph from the patient information document, for discussion and analysis. See Figure 6.

The first meta-semiotic task, *representational meta-function,* concerns how people, places and objects in an image signify what the picture is about by incorporating actions or concepts. According to Harrison (2003), *representational meta-function* can have a *narrative* or *conceptual* structure.

In the *narrative* structure, the image represents an action or reactions that include vector relationship between the represented participants (RPs), as seen by contact or orientation (Harrison, 2003).

In the *conceptual* structure, Harrison (2003) states that the images represent concepts, which can be considered to be:

- *Classificatory*, through grouping of RPs
- *Analytical*, in the sense that the image has parts, called *attributes* that make up a whole, called the *carrier*
- *Symbolic,* where the images represent or carry some meaning.

Figure 6, taken from the patient information document, shows a provider caring for a patient and can be analyzed based Harrison's meta-semiotic tasks.

Figure 6: Project Photo Example of Medical Image (Shutterstock.com)

The figure shows a provider and a patient in a clinical setting where the provider is taking the patient's blood pressure. This image represents an action and a concept of care. The image has a narrative, in the action taking place, but it also has a conceptual side. Here, the image is classified as being a healthcare setting, and it has parts made up of the provider and the patient, which serves as the whole. The image can also be symbolic because it represents a healthcare relationship and a perceived need for care for the senior citizen patient.

The second meta-semiotic task, *interpersonal meta-function*, is about how the image engages the viewer and encompasses the relationship between participants and viewers, including how close the represented participants (RPs) are to the viewer, the horizontal angles created between the RPs and the viewer, and between the RPs in the image themselves (Harrison, 2003).

Harrison (2003) recommends using other aspects, including:

- Creating strong viewer involvement, such as a using the human face—which people readily respond to
- Creating visual demand, which addresses the viewer, causing him or her to relate to the RPs in the image
- Using intimate distance, where space between RPs in the image communicate something about the RPs relationship.
- Making note of angles, where the RPs have a relationship between each other and the viewer

These aspects can also be demonstrated by Figure 6. The patient in the image is smiling, which generates a positive response from the viewer. Patients with cancer routinely have had their blood pressure taken, so this image causes the viewer to relate to the action. When it comes

to the intimate distance it should be noted that the RPs have a close physically proximity, while the horizontal vector places them on equal ground in the viewer's perception. The image's perspective is close to the viewer, which also creates more intimacy than if it were depicted from a greater distance.

The third meta-semiotic task, *compositional meta-function,* is about how the first two (representational and interpersonal meta-functions) integrate (Harrison, 2003). Harrison (2003) calls this "visual syntax." Harrison (2003) states that this meta-function takes into consideration the following:

- Information value, where the image sends a rhetorical message to the viewer
- Salience, where size, focus and foreground, also send a rhetorical message regarding importance and relationship
- Framing, where the image is set off from the page by its borders
- Modality, where photographs suggest a greater sense of reality than other mediums, such as drawings or paintings.

The image in Figure 6 sends a rhetorical message that the provider and patient have an intimate, friendly relationship, which is central to the photograph and in the viewer's mind. The image of the blood pressure cuff is central, with both the provider's and patient's attention and gaze creating a vector toward the blood pressure cuff. The photograph on the white page creates a snapshot of a moment in time that appears both authentic and relatable.

4.3.5.2. Non-Medical Images and Symbols

The use of non-medical photographs and images within the patient information document is based on studies that show that images from nature have been found to improve patient

experience in a health care setting (Hathorn and Nanda, 2008). The use of symbols is based on historical interpretations of signs and symbols (Frutiger, 1989).

My choice of photographic images in the patient information document in this category take into account Harrison's (2003) recommendations, along with color choices, discussed previously, which add another dimension of meaning to the visual message. Hathorn and Nanda (2008) present a review of the literature relating to the relationship between art and healing, where they explore the emotional impact of art on the ill.

A main focus of Hathorn and Nanda's (2008) review (as cited in Ulrich and Gilpin, 2003) regard the relationship between art work from nature and patient comfort. In the study, images showing calm or slow moving water, verdant foliage, flowers, foregrounds with spatial openness, and birds and other non-threatening wildlife correlated with improved patient comfort. Assessments of patient comfort included the need for pain medication, as well as blood pressure and pulse readings. A study by Carpman and Grant (as cited in Hathorn and Nanda, 2008) also reported that patients prefer art depicting natural scenes over the following other types of images, including urban scenes, still life, sport scenes, or abstract art. See Figure 7 for examples of nature photography taken from the patient information document.

Figure 7: Examples of Nature Art Used in Patient Information Document
Calm and slow moving water, non-threatening wildlife, and flowers are recommended to improve patient comfort levels.

Ulrich and Gilpin (as cited in Hathorn and Nanda, 2008) also present research, which supports the data showing that people prefer natural images because of evolutionary tendencies to find nature calming and restorative. Reber, Schwarz, and Winkelman (as cited in Hathorn and Nanda, 2008) noted that the more familiar the patient is with the image, the more positive his or her response. For this reason, I have included natural photographs from the surrounding geographical area for use in the patient information document, which has been designed for a fictitious medical center based in Montana called "Western Valley Medical Center." The natural images in the document came almost exclusively from my own photographic work, taken in Montana. Most images were taken within 30 miles from Butte, where I live. These images could be exchanged for any region of the country, to better relate to any geographical target population.

When choosing the design for the cover of the patient information document, I followed the CDC (2009) recommendation to "make the cover attractive to your intended audience. If the cover does not include images and colors your intended audience likes, they may not pay attention to it." Following the suggestions of the CDC (2009) and Hathorn and Nanda (2008), the cover image shown in Figure 8 provides a desirable, local, and familiar photograph for the fictitious, Montana cancer center used in the document prototype.

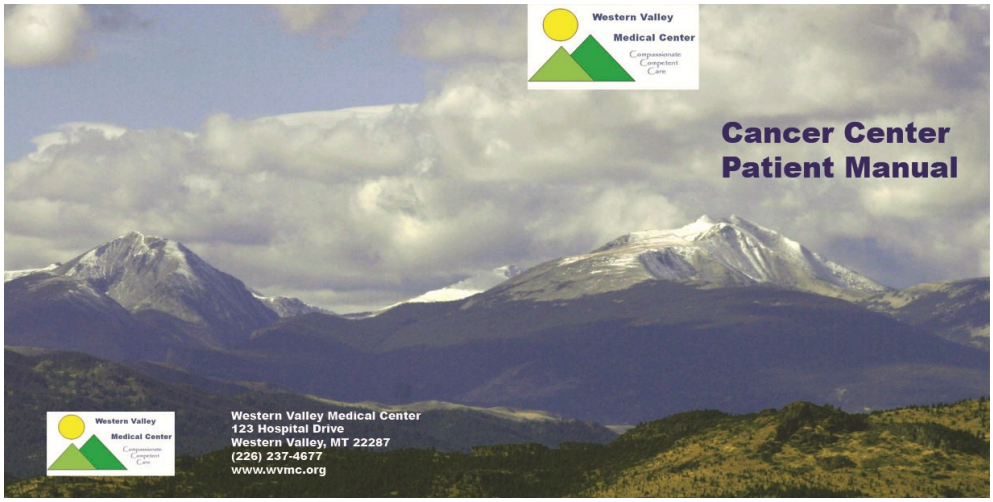


Figure 8: Cover Image
(front and back)

The color choices reflect the document's analogous color scheme, using blue, green, and yellow. The picture shows spatial openness and familiar views. It also contains a fictitious logo for the "Western Valley Medical Center," with symbols in the shape of a circle and triangles, which symbolize the sun and mountains. The interpretation of symbols will be discussed further in the next section.

4.3.5.3. Interpretations of Signs and Symbols

Signs and symbols and how people perceive them have their own place within the patient information document. Frutiger (1989) outlines design and meaning of signs and symbols and discusses some human traits that have shaped our perception.

Frutiger (1989) discusses horizontal optical capacity of the human field of vision, which is more extensive in the horizontal dimension than the vertical. This aspect of visual capacity can be applied to the orientation of books, including the patient information document, which open in this direction.

According to Frutiger (1989), within human perception, certain shapes and designs have come to symbolize certain meanings. Examples are included in Table 6.

Table 6: Signs, Symbols and Their Meanings (Frutiger,1989)

Sign/Symbol	Perceived Meanings
Circle	Circles have a strong symbolic relationship with the sun and the planets, and the eternal circle of life.
Triangle	Triangles create a sense of stability and permanence, like the pyramids or mountains.
Square	Squares symbolize boundaries, which provide protection, and the four points of the compass.

Frutiger (1989) also notes that Gestalt psychology showed that the human eye is first drawn to horizontal and vertical movements. The use of the triangle in the logo includes this concept.

Each shape's perceived meaning in Table 6 also supports the medical rhetoric about the cancer center, and correlates with the document's goal to ease anxiety through color choice. In addition to circles and triangles, square shapes are used in the document to create boundaries around information and images, and to create a sense of protection.

Two recurring images in the document include a question mark and a compass rose. In written English, the question mark is a symbolic image for interrogative sentences and a logical choice for a patient information document designed to help answer patient questions. The second image is the compass rose, which symbolizes direction, and is primarily coupled with the question mark in the document design. Patient information documents, by their design, are created to help guide people through illness by providing information on disease and treatment. The symbol serves as a positive metaphor for this function. See Figure 9.

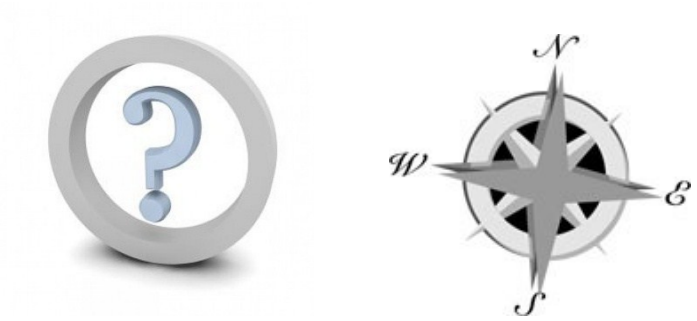


Figure 9: Symbols Used in the Patient Information Document
(Question mark fromwww.freepik.com, compass rose from www.clipart-for-free.blogspot.com)

5. Project Procedure

In addition to conducting an extensive literature review, prior to designing the document, I reviewed industry standard patient information documents from five major cancer centers within the United States. These centers included:

- Dana-Farber/Brigham & Women's Cancer Center (DF/BW), in Boston, Massachusetts
- Mayo Clinic Cancer Center (MAYO) in Rochester, Minnesota
- M.D. Anderson Cancer Center (MDA) in Houston, Texas
- Memorial Sloan-Kettering Cancer Center (MS-K), New York, N.Y.
- Seattle Cancer Care Alliance (SCCA) in Seattle, Washington

For the medical content, I conducted research on cancer-related technical material, and I re-wrote that material according to guidelines addressed in the literature review (NIH, 2010). I requested permission from the local Cancer Center at St. James Healthcare in Butte, Mont. to have providers review the material for medical accuracy. I also included selected medical definitions for a glossary of cancer-related terms. Readability testing and usability testing

confirmed the document's utility and usability, and the project moved into final design phase. These steps will all be discussed in more detail, below.

5.1. Evaluation of Industry Standards for Patient Information

I contacted the previously listed medical centers and requested examples of their cancer-related patient information documents. As they arrived, I analyzed features before choosing which features to include in my own document. Patient information documents from MS-K were exclusively online, so they were not used for analysis or to determine content choice for my printed document.

The majority of the features in my document design are present in the four remaining cancer center documents. A breakdown is included in the following four tables, numbered 7-10. In each table, industry standard characteristics are displayed alongside the features I included in my patient information document model, under the heading, McGarvey.

It should be noted that the analysis was done on documents, which I received from the different cancer centers and may not accurately reflect all patient information documents currently in use at the various facilities.

Table 7 includes information on the physical attributes of the document.

Table 7: Comparison of Industry Standard Features of Patient Information Documents, *Physical Document*

Patient Information Documents					
Features	**DF/BW**	**MAYO**	**MDA**	**SCCA**	**MCGARVEY**
Physical Document:					
Size	8.5" x 11"	8.5" x 11"	8.5" x 11"	8.5" x 11"	8.5" x 11"
Total of pages	180	78	122	210	140
Binding	Folder folio plus spiral Book	3-folio booklets	Spiral book	Folder folios plus spiral book	3-ring, with spiral final Planned
Numbered pages	+ Sequential by Section	Introduction: - Chemotherapy & Radiation: + Sequential	+ Sequential by section	-	+ Sequential
Table of Contents	+	Introduction: - Chemotherapy:- Radiation: +	+	+ By section content (bullets),with no page numbers	+
Tabs	-	-	+	+	+
Pocket Folders	+	-	+	+	+
Glossary	+	-	-	+	+
Index	-	-	-	-	-
References	-	-	-	-	+

All documents analyzed in Table 7 were consistent in overall size, and I selected the same size for my document. Total page number varies by cancer center. My document serves as the median number of pages, when compared to all documents analyzed. The type of binding varies by document size, with a proportional necessity for spiral biding with larger total page numbers. My prototype mock-up for the usability study done on the document (which will be

discussed later in the paper) used a three-ring binder, but would be published with a spiral binding in its final form, based on total page number.

Page numbering of the different cancer center documents varied and included no page numbers, sequential numbering by section, and sequential numbering throughout the document. I chose to include sequential page numbers for the introductory material, and throughout the rest my document, which I believe is the best method to avoid confusion.

Almost all documents had some form of table of contents, with the exception of introductory and chemotherapy folios for MAYO. I have included this element for organizational reasons (NIH, 2010). The presence of tabs, pocket folders, and glossaries in documents vary by cancer center. I chose to use all these elements in my design. Both indexes and references were absent in cancer center documents, though I included a reference list in my patient information document. Industry standards did not include the use of an index, and the table of contents and tabs in my design make the use of an index unnecessary.

Table 8 addresses document design.

Table 8: Comparison of Industry Standard Features of Patient Information Documents, *Document Design*

	Patient Information Documents				
Features	**DF/BW**	**Mayo**	**MDA**	**SCCA**	**McGarvey**
Document Design:					
Headings	+	+	+	+	+
Tables	+	+	+	+	+
Figures	+	-	-	+	+
Bullets	+	+	+	+	+
Medical Photos/images	+	+	-	-	+
Art Photos/images	-	-	+	+ Cover	+
Color	+ Cover	Introduction:+ Throughout Chemotherapy:+ Cover Radiation: + Throughout	+ Cover	+ Cover	+ Throughout

Table 8 focuses on the use of design elements, including: headings, tables, and bullets, which were consistent in all documents. These recommended design elements (NIH, 2010) were included in my document. The use of figures, medical, and artistic photos and images varied, and I have used these elements in my document based on recommended design principles and information previously discussed in the literature review (Aldridge, 2004; CDC, 2009; Hathorn and Nanda, 2008). The use of color printing varied from use in covers alone, to use throughout the entire document. Because of the literature review support for the link between color and emotion, I included color elements throughout my document (Hathorn and Nanda, 2008; Mahnke, 1996). Table 9 outlines various components of the patient information documents.

Table 9 Comparison of Industry Standard Features of Patient Information Documents, *Document Content*

	Patient Information Documents				
Features	**DF/BW**	**Mayo**	**MDA**	**SCCA**	**McGarvey**
Document Content:					
Welcome/Intro	+	+	-	+	+
Cancer Cause Explanation	-	-	-	-	+
Cancer Treatment Explanation	+	+	+	+	+
Side Effects	+	-	+	+	+
Appointment Tips/Questions List	-	-	-	+	+
Space for Patient Notes/Questions	-	Introduction: - Chemotherapy:+ Radiation: -	+	+	+
Resource List	+	-	+	+	+
Space for Patient List of Resources	-	-	-	-	+
Contact Information	+	+	+	+	+
Space for Patient's Contacts	-	Introduction: - Chemotherapy:- Radiation:+	-	-	+
Medical Job Descriptions	+	Introduction: - Chemotherapy:+ Radiation:+	-	-	+

Table 9 shows varying use of welcome or introductory material. I have included both these elements, since a secondary focus of my document was to counter feelings of fear and loss of control (Donnelly, 1995). The literature also supports that the use of orientation- related information decreases patient anxiety (Rawl, 2002; Deshler, 2006).

The documents showed consistent use of some explanation of treatment, with no explanation of what caused cancer. I included the cause of cancer in my document to support my project's goal of addressing patient fear and loss of control, and cultural codes (Donnelly, 1995; Borchers, 2006).

Side effects were addressed in most cases. There was variance in the use of appointment tips or question lists, with similar variance in providing patient's space for their own notes in these areas. I included all these elements (Aldridge, 2004).

The use of resource lists was variable, with no provision for patient's own list of contacts. I included both resource lists, and a space for patients to record their own resources (Aldridge, 2004). The use of contact information was universal, but providing spaces for patient's own contacts was not. I included this element (Aldridge, 2004). The use of photos of employees was variable, as was identifications of the employees. I have included both elements.

Table 10 outlines the use of quotes and cancer-related poetry within patient information documents.

Table 10: Comparison of Industry Standard Features of Patient Information Documents, *Other*

	Patient Information Documents				
Features	**DF/BW**	**MAYO**	**MDA**	**SCCA**	**MCGARVEY**
Other:					
Quotes	-	+	-	+	+
Poetry	-	-	-	-	+

As Table 10 shows, there was some use of quotes from patients by MAYO and SCCA, but no use of cancer related poetry by cancer centers in my analysis. In my prototype, I used on inspirational quote by an unknown author, and included a non-rhyming cancer-related poem that has been in circulation since at least 1980, when I first acquired a copy from a hospice organization volunteer. As previously stated, I included the poem in the interest of addressing emotional issues faced by people with cancer. According to Aldridge (2004), educational material for patients should be, "…mindful of the cultural needs of particular groups." The evidence of the patient's perspective and experience of cancer constitutes a cultural group and the anonymous poem, "What Cancer Cannot Do," has become part of the iconography of the disease. The familiar poem is marketed for purchase on numerous, commercial online sites (for example, www.amazon.com, www.choosehope.com, etc.). I have placed it inside of the back cover of the patient information document and include it here:

What Cancer Cannot Do

Cancer is so limited:
It cannot cripple love,
It cannot shatter hope.
It cannot corrode faith,
It cannot destroy peace.
It cannot kill friendship.
It cannot suppress memories.
It cannot silence courage.
It cannot invade the soul.
It cannot steal eternal life.
It cannot conquer the spirit.

The only notable additions I made to my patient information document that differ from industry standards were to include an explanation of cancer's cause, references for the patient information document, and the cancer-related poem.

5.2. **Prototype Production**

With knowledge of industry standards for patient information documents, information obtained from the literature review, and research on communication theory and design principles previously addressed in this paper, I created a working outline of the patient information document in the form of a manual for patients with cancer.

I took into consideration that there are more than 100 different types of cancer, and chose to refine the focus of the document to include the most common types of cancer, which include prostate, breast, colorectal, and lung cancer. These four types of cancer will make up roughly 52% of all new cancers diagnosed in 2012 (ACS, 2012).

I adjusted my outline and began searching for information about these particular types of cancers, regarding cause, treatment, and terminology. Next, I searched for medical content and glossary information. I obtained the bulk of medical and technical information for the document from the American Cancer Society (ACS) and the National Cancer Institute (NCI) Web sites, and supplemented it with other sources, as needed. The ACS and NCI Web sites have reliable, consistent information and have been noted as being most recognizable by cancer patients (Longo et al., 2009). This choice was an important component for consistency, in the event patients go beyond the document and look to access more detailed information from these sites.

As I collected the medical content, I analyzed and rewrote the material, taking into account the NIH plain language initiative (NIH, 2010), recommendations from the CDC (2009), and discrepancies between patient and provider perspective (Donnelly, 1995; Kleinman , 1988).

The NCI had the most complete dictionary of cancer-related medical terms (6,800 words), and its content is reported to be updated every three months (NCI, 2012). The Web site's dictionary also included phonetic spelling of pronunciations, along with an icon to click on in order to hear the word being spoken. I scrolled through the online dictionary and selected

words, phonetic spellings, and definitions and constructed a glossary of terms for potential use. Each time a medical term was introduced into the patient information document, I included it in the document's glossary. In doing so, it became evident that the density of medical terms was extremely high in the text.

From a usability perspective, it occurred to me that it would be easier for patients with cancer to have the phonetic pronunciation with the word more readily available, rather than flipping back and forth to the glossary multiple times on each page for correct pronunciations. However, including the phonetic spelling each time the word appeared would be cumbersome. To solve the problem, I included the phonetic spelling in the text the first time a word appeared in a given section of the document. The rationale was that understanding the proper way to say the word is an important element in bridging communication gaps, especially from the patient perspective regarding questions directed at nurses, oncologists, or other providers involved with their care.

Simultaneously, I worked on layout and design of the document, relying on the evidence-based rationale for choices, which was previously addressed in the paper. I gathered images from my own photography collection, took new ones to fill spaces, and used on-line sources for free clip-art and medical stock photos to include in the document. I constructed figures and diagrams to simplify concepts, using Adobe Illustrator, saving files in Joint Photographic Experts Group (JPEG) format, and then importing them into the document.

I designed my initial working prototype using Microsoft Office Publisher software. As sections were completed, I began to build a three dimensional "mock-up" version of the document prototype. I used a three-ring binder, plastic see-through sheet protectors, and

constructed tabbed pages and folder pages, when commercial versions did not suffice. As I progressed, I constructed a working style guide for consistency.

Initially, the three dimensional prototype was in a constant state of revision. As I constructed each section, I made note of design flaws and made necessary changes, in accordance with the literature review. For example, in my prototype, I became aware that the section entitled "When Cancer Treatment Doesn't Work" was juxtaposed to the beginning of the "Personal Treatment Plan" section of the document. Taking into account a patient's fear and feelings of loss of control (Donnelly, 1995), I chose to rearrange the content so patients would not enter the treatment section with any anxiety concerning poor outcomes, based on poor design.

With the prototype completed, it was time for testing. I included both readability testing and usability testing to evaluate the document prototype.

5.3. Readability Testing

Longo et al. (2009) reported that 16-38 % of adults are illiterate or have low literacy skills, which creates difficulties in access and use of health information. The CDC (2010) cites statistics from the National Assessment of Adult Literacy (U.S. Department of Education) that 30 million adults struggle with basic reading tasks. The NIH recommends target reading levels remain between the grade 4 to grade 8 levels (NIH, 2010). The CDC promotes the use of clear and understandable language in health communication (CDC, 2010), for similar reasons.

The CDC (2010) recommends using formulas for calculating readability including the SMOG (Simply Measure of Gobbledygook) formula, which relies on polysyllabic word counts (three and greater) in a limited number of sentences (30). See Appendix B for the SMOG

formula. This assessment put my patient information document at a disadvantage, based on the number of polysyllabic medical terms used in cancer treatment.

I conducted the readability test using the first page of the treatment sections defining cancer, surgery, and chemotherapy. As I feared, with the density of medical terms and phonetic spellings, the SMOG formula placed the document at a grade12 reading level. There was slight improvement, when applying the SMOG formula to assess less technical areas, which included the welcome, list of common questions, and hospice care sections, where the SMOG rating dropped to a grade 11 reading level.

The CDC (2010) also suggests using the Fry formula, which is listed in Appendix B, and uses both the number of syllables and number of sentences (per 100 words), and makes partial corrections by omitting counts for proper nouns and numbers. I used the same content used in the SMOG analysis listed above, for the Fry analysis. The Fry analysis rated the patient information document at grade level 13. But, when applied to the less technical information used in the SMOG formula analysis, the Fry analysis rating drops to the grade 7 reading level, which is acceptable to the NIH standards (NIH, 2010). See Table 11 for comparisons.

Table 11: Readability Testing Comparisons

Material Content	SMOG Formula	Fry Formula
Technical	Grade 12 (88 polysyllabic words)	Grade 13 (165 syllables/4.6 sentences)
General	Grade 11 (65 polysyllabic words)	Grade 7 (141 syllables/6.9 sentences)

Though the overall results exceeded the NIH recommendations of grade 4 to grade 8 reading levels for documents, given the nature of the material, I see no way to improve the readability without removing the terminology used in cancer treatment, necessary to explain and

interpret the language of oncology. As Chelf et al. (2001) reported, easy to read material may not always resolve communication gaps.

The glossary of cancer-related terms, which I have included in the patient information document, helps rectify the disparity. Although readability failed to consistently fall in the recommended range on most counts, the results confirm my argument that the language of cancer is difficult to comprehend, reinforcing the need for the document.

5.4. **Mid-stage Usability Study**

I included a mid-stage usability study of the patient information document, as a form of iterative design, so that any necessary design or content changes could be implemented prior to constructing the final document (Neilsen, 2000). I determined a target population best equipped to evaluate a patient information document for people with cancer composed of people who had experienced cancer diagnosis and treatment. The target population included volunteers over the age of 18 who had been diagnosed with cancer and lived within southwest Montana.

Next, I constructed survey questions, which were designed to determine the document's *utility* (whether it provided the features that cancer patient's needed) and its *usability* (how easy and pleasant those features were to use) (Nielson, 2000).

My survey included demographic questions concerning age, sex, type of cancer diagnosed with, and type of treatment received. This information would confirm that the participants did fit into the target demographic group, and it served to help recognize any demographic-related trends in results. Including health related demographic information required the use of both personal health information consent and traditional informed consent forms used in surveys (Blair and Czaja, 2005).

The informed consent was accompanied by a subject information sheet I constructed. It included: project title, contacts, purpose and procedures, benefits and risks, confidentiality information, voluntary participant withdrawal clause, and contact information for any additional questions. Both these forms, along with the survey, are included in Appendices C and D.

In addition to demographic information, I included closed-ended questions, involving opinions and ratings of the patient information document regarding utility and usability, which would include both verbal descriptions of satisfaction and corresponding numerical values, ranging between 1 and 5 (with one being the least satisfactory and 5 being the most satisfactory). I also included an open-ended comment section.

I drafted a request letter to recruit volunteers, which would run in the local daily newspaper. It included information about the project and contact information. The request letter with the participant appeal is included in Appendix E.

Because of the plan to use human subjects for the survey, the project required approval from the University of Montana's Institutional Review Board (IRB) and completion of human subject education training. Both the IRB approval form and the National Institutes of Health certificate of completion of the "Protecting Human Research Participants" online training course appear in Appendix F.

The project material was approved by the University's IRB, and I sent my request letter to the local newspaper. The request appeared in the Tuesday, October 23, 2012, and the Wednesday, October 31, 2012, editions of *The Montana Standard.* I received a total of nine responses to the requests. Five completed the survey and consent forms. One person made an appointment to complete the survey, but did not come to the appointment. Three people offered to participate in the survey, only if I did not have enough volunteers already. All three of these

conditional volunteers were female senior citizens who told me that they had experienced breast cancer. Since the demographic was already sufficiently represented, so I did not pursue their input from these women for fear of introducing bias to the study and possibly skewing the data heavily toward breast cancer survivors. The five participants that completed the survey already had provided the necessary number required for usability studies (Nielsen, 2000). The U.S. Department of Health and Human Services (2012) statistics show that a usability study conducted with five participants has a 97% chance of finding a usability problem.

I had requested and was approved to use of the Technical Communication Department conference room to conduct the survey, and I obtained the necessary keys to the site. I reserved 45-minute time slots for participants on several different days to review the document and take the survey. I estimated that the survey would take approximately 30 minutes and left time between appointments to protect the confidentiality of the participants.

At each appointment, I obtained the signed informed consent and release of personal health information forms prior to having participants begin the survey. I provided a few verbal instructions to supplement the written ones, and then I left participants alone to complete the survey. Volunteers were asked to place the completed survey in a sealed envelope and return it to me when they completed the survey. I made note of any parting comments on the envelope's exterior. Separate folders for signed consent forms and survey responses were stored in two, separate, locked file cabinets, according to IRB protocol.

Result analysis is shown in Tables 12 through 14. Table 12 shows a breakdown of survey participants by age, sex, type of cancer, and type of treatment.

Table 12: Survey Result Analysis, Demographics

Response					
Demographic Information	**Subject 1**	**Subject 2**	**Subject 3**	**Subject 4**	**Subject 5**
Confirmation of Cancer Diagnosis	Yes	Yes	Yes	Yes	Yes
Type of Cancer	Breast	Breast	Breast Sarcoma	Lymphoma	Colon
Treatment Received	Surgery Chemotherapy Radiation	Surgery Chemotherapy	Surgery Chemotherapy	Chemotherapy Radiation	Surgery Chemotherapy
Age as of 1/1/2012	61	71	60	60	72
Sex	Female	Female	Female	Male	Male

The demographic information in Table 12 shows that 60% of the participants were women and 40% were men. All participants were over the age of 60, which correlated with the ACS (2012) statistics that state that 77% of people diagnosed with cancer are age 55 and older. The data shows that 60% of the participants had breast cancer, with the remaining 40% diagnosed with lymphoma or colon cancer. It should be noted that one participant had experienced both breast cancer and an unspecified form of sarcoma.

Results showed that 80% of the participants had a type of cancer targeted in the document's content. The study did not include any participants with prostate or lung cancer, which are two of the most common types of cancer (ACS, 2012). The data shows that 80% of participants had some type of surgery, while 100 % had some type of chemotherapy, and 40% had some type of radiation therapy.

Overall, the pool of participants seemed balanced according to sex, age, and treatment experience. Not all of the four most common types of cancer were represented by participants, and it should be noted that that participant's responses to the survey may not accurately reflect opinions from those diagnosed with lung, prostate, or other types of cancer.

Table 13 assesses the ease of use of the document. Results are presented by percent of participants (%) and ratio of participants (#) responding.

Table 13: Survey Result Analysis, *Usability Data*

Response Percentages %(Ratio of Responses)							
Usability Data	**1 Poor**	**2 Fair**	**3 No opinion**	**4 Good**		**5 Excellent**	
				%	**#**	**%**	**#**
Size of manual (8 ½ x 11 inches)				40	(2/5)	60	(3/5)
Order of information				20	(1/5)	80	(4/5)
Tabs						100	(5/5)
	1 With much difficulty	**2 With some difficulty**	**3 No opinion**	**4 With some ease**		**5 With much ease**	
				%	**#**	**%**	**#**
Locate Section III in the manual				20	(1/5)	80	(4/5)
Locate Personal Treatment folder and the Appointment/Notes Folder						100	(5/5)

The usability data in Table 13 addresses the dimensions of the document, the order the information is presented, the tabs used to divide sections, and ease in locating a section and items included within that section. The participants consistently rated these elements or tasks associated with usability as either being good to excellent or having been done with some or much ease. The majority rated elements or tasks at the highest level of the 1-5 scale. The document received the least favorable percentage of excellent ratings on the dimensions, though the 8 ½ x 11 inch size was consistent with other documents used for this purpose at major cancer centers. Table 14 assesses the document's content. Results are presented by percent of participants (%) and ratio of participants (#) responding.

Table 14: Survey Result Analysis, Utility

	1 Not at all helpful	2 Not too helpful		3 No opinion		4 Somewhat helpful		5 Very helpful	
		%	#	%	#	%	#	%	#
Nature Photos		20	(1/5)	20	(1/5)	20	(1/5)	40	(2/5)
Contact Information						20	(1/5)	80	(4/5)
Welcome				20	(1/5)			80	(4/5)
Cancer Related Diagrams						20	(1/5)	80	(4/5)
Table of Contents								100	(5/5)
Medical Information Photographs						40	(2/5)	60	(3/5)
Explanation of What Cancer Is								100	(5/5)
Explanation of Treatments								100	(5/5)
Tips for Meeting with Healthcare Providers						20	(4/5)	80	(4/5)
Personalized Treatment Folder								100	(5/5)
Commonly Asked Question List								100	(5/5)
Personal Questions/Appointment Note Folder						20	(1/5)	80	(4/5)
Healthcare Provider Job Descriptions						40	(2/5)	60	(3/5)
Personal Resource List								100	(5/5)
Local/On-line Resource Folder				20	(1/5)			80	(4/5)
Glossary of Cancer Terms						20	(1/5)	80	(4/5)
References						20	(1/5)	80	(4/5)
Inspirational Quote				20	(1/5)			80	(4/5)
Cancer Related Poetry						20	(1/5)	80	(4/5)

The utility data in Table 14 addresses desirability and helpfulness of components of a manual for patients with cancer. Participants rated the components as being helpful or very helpful, most often. The components that showed mixed responses included: nature photographs, welcome, local and on-line resource folder, and inspirational quote. In all these cases, the majority still rated these elements at least somewhat to very helpful.

Checking for trends, it was evident that the lowest ratings had been given by two of the participants in the study. These participants included Subject 3, a 60-year-old woman who had experienced both breast cancer and a type of sarcoma, and Subject 4, a 60-year-old man who had been diagnosed with lymphoma. The lower approval ratings could be related to the document's focus on prostate, breast, lung, and colon cancers. This observation is supported by an anecdotal comment made by Subject 4 when he submitted his survey. Subject 4 stated: "It didn't have a lot of information about the kind of cancer I had."

Of the remaining elements, most showed at least 80% favorability for being very helpful. Two components, medical photographs and local and online resource folders, were rated as being very helpful by 60% of participants and as being somewhat helpful by 40%. Again, analysis of responses showed that the lower ratings were given by Subject 3 and Subject 4. Overall, the majority of participants rated all elements with either a somewhat helpful or very helpful rating.

The survey also included a space for comments. Only two out of the five participants wrote comments. One participant, Subject 2, a 71-year-old breast cancer survivor wrote, "This was very well done." The other participant, Subject 3, a 60-year-old women who had experienced both breast cancer and a type of sarcoma, wrote, "Personal appt. & Note folder might be placed in front or otherwise highly separated from the rest of the book so most easily found. Maybe small notebook slipped into front cover? Same with personal resource list."

The subject's idea to include a pull-out resource for patient convenience has merits in function, but it would create difficulties in production and printing logistics as well as printing costs. Also, the final document would be printed in a spiral binding, which would be easier to tote than the three-ring binder prototype, and could possibly address this suggestion.

My conclusions for the analysis of the usability survey are that results did not indicate any usability flaws, or the need to change the document format at this time.

5.5. Input From Providers

In addition to obtaining input from patients with cancer in a usability study, I requested permission from the local hospital, St. James Healthcare in Butte, Montana, to have providers at the hospital's Cancer Center review the medical content of the manual. Permission was granted. Though the information I included came directly from reliable sources (ACS and NCI), I felt that having providers who worked in the field review the information would be wise in the interest of accuracy. Of those who returned drafts of the sections that applied to their specialty, none made any significant remarks or corrections concerning the medical accuracy of the information. However, I did receive some unsolicited, anecdotal comments about the document's utility, choice of content, and organization of that content.

Employee 1, a dosimetrist involved with radiation dosing calculations, commented on the use of phonetic spellings in the text and called them "tiresome," recommending excluding them. Employee 1 also felt that some of the information was "…still a little too in-depth."

Employee 2, a radiation therapist involved in administering radiation treatments, made the following observation: "The patients seem to be overwhelmed and feel bombarded with too much information. Those that want information get it off the Internet." Employee 2 also suggested that document section on radiation therapy be reduced to "…two or three paragraphs."

Employee 3, another radiation therapist, made suggestions on content and wording, and referred to general information about one type of therapy as being "vague" and offered a more in-depth explanation. Employee 3 also suggested that phonetic spellings be moved to a glossary.

Employee 4, a medical oncology nurse who administers chemotherapy, commented, "This is very good. I liked the phonetic spellings," and suggested a reorganization of the document's "Other Therapies" section in a different hierarchy than presented by the ACS and NCI.

The unsolicited comments were contradictory to each other in the case of depth of information and use of phonetic spelling. Other comments were also contradictory to the information contained in the literature review on patient information documents and the patient perspective.

For example, in regard to depth of information, Chelf et al. (2001) reviewed a decade of reports on cancer-related patient education and concluded that "patients with cancer want the maximum amount of information about their illness," and that "easy-to-read materials do not always have the same level of detail as those written at a higher level and may not resolve a knowledge gap."

In regard to use of the Web, with 77% of newly diagnosed patients with cancer falling into the 55 and older age group, reliance on the Web only represents half of senior citizens (Raine, 2012). Longo et al. (2009) showed that not all patients with cancer will use the Web as an information resource, even if they are aware of it. Furthermore, Nielsen (2002) shows that that seniors have difficulty using the Internet, with a lower success rate than younger people.

As to the use of phonetic spellings, no comments were made by patients with cancer completing the usability survey on this matter. My thoughts on including them in the text body the first time they appeared, was one of usability to avoid constant flipping to the back of the document for pronunciations. It would be advisable to include a question specifically about this feature in a future usability study to resolve this issue.

I did review the organization of the "Other Therapies" section, and regroup the material based on the comment made by Employee 4. The comment was valid, and I altered the order of the information accordingly.

Overall, I believe that the majority of the unsolicited responses presented a clear example of differences in the provider and patient perspectives of disease, outlined in the literature review (Kleinman, 1988; Donnelly, 1995), and then only serve to support the need for patient information documents. What the providers at the local facility think the patient wants and needs is contradictory to what the research shows that patients with cancer want and need.

This observation is especially true, when anecdotal comments made by several survey participants are considered. Subject 2 made the following comment when handing in her sealed survey envelope, "I wish I had something like this when I went through cancer." Those sentiments were also reflected by Subject 5, who said, "My doctor did a good job explaining, but I wish I had something like this."

5.6. Final Layout and Design

With results of the readability testing, usability study, and additional assessment of medical accuracy supporting the overall document prototype design, I converted the document to PDF format for inclusion in this meta-document. There were no difficulties encountered in this process.

The document is attached in Appendix A . It should be noted that tabbed and folder pages appear in a two dimensional format. Supplemental information contained in the document's pocket folders on resources and employee profiles is attached at the end.

6. Conclusions

Cancer and cancer care are part of the human condition (Mukherjee, 2010; Foucault, 1994), as are differences in perception between health care providers and patients with cancer (Donnelly, 1995; Kleinman, 1988).

Evidence shows that patients with cancer want information about their disease (Chelf et al., 2001) and that information can serve to reduce patient anxiety (Rawl ,2002; Deshler et al., 2006).

The literature review clearly demonstrates that patients and providers have different perspectives on cancer as a disease and an illness, and that discrepancies exist between knowledge, understanding, perspective, and vocabulary, as associated with cancer (Kleinman, 1988; Donnelly, 1995; Sontag, 1977). Providers and patients also operate under a different set of cultural codes for cancer (Thompson, 2009; Vance-Staiano, 1979), which compound communication gaps.

Printed media is confirmed as a preferred medium by patients with cancer (Longo et al., 2009). Though patients with cancer are aware of Web resources, they do not always make use of them (Longo et al., 2009). Many cancer patients are senior citizens (ACS, 2012). When senior citizens do access the Web, they do not always do so successfully (Nielsen, 2002).

When it comes to information about cancer, patients benefit when information is presented in easily understood language (NIH, 2010), although this approach can be a challenge when dealing with medical information and related terminology (Chelf et al., 2001).

Information, such as printed media, can also be used to help diffuse some of the negative emotional aspects of being diagnosed with cancer, such as anxiety. (Deshler et al., 2006; Rawl, 2002).

When design components that show emotional correlation to negative feelings are considered and avoided, and those that show positive correlations are included, this information can further reduce patient anxiety. These elements include color (Mahnke, 1996; Eiseman, 2006), typography (Brumberger, 2003; Mackiewicz and Moeller, 2004), medical photographs and figures (CDC, 2009; Harrison, 2003), natural photographs (Hathorn and Nanda, 2008), and images and symbols (Frutiger, 1991).

Readability of the document tested at higher grade levels than recommended (NIH, 2010; CDC, 2009), but could not be avoided considering the medical content that needed to be explained and patient's needs concerning this information (Chelf et al., 2001).

Usability survey testing results concerning the patient information document prototype were primarily favorable, confirming the design's usefulness and the utility of its content. Unsolicited, anecdotal comments from providers served to confirm differences in perspective between providers and patients, when compared to survey results, patient's anecdotal comments, and the literature review.

Overall, favorable usability survey results also suggest that design elements such as images and color, introduced to counter feelings of fear and loss of control (Kleinman, 1988; Donnelly, 1995) served their purpose.

Therefore, I conclude that the production of an evidence-based patient information document for patients with cancer is a direct application of technical communication that serves to bridge communication gaps between health care providers and patients, with great potential to improve the patient experience.

7. Recommendations

Although the project was constructed using evidence-based design, and the usability survey results and survey participant's anecdotal comments suggest it is successful at serving its intended purpose, the document could still benefit from some additional iterative design and input.

The shortage of participants from groups representing the most common types of cancer, including lung, prostate, and colon cancer, could skew results and overlook diagnosis-specific utility design flaws in the content. An additional usability study collecting more participants from each of the targeted areas would eliminate this potential flaw.

Readability issues could be addressed by a usability study focusing on text, to gain input on whether patients found the information to still be too difficult to read, even with in-text explanations and a glossary of terms.

Anecdotal comments on content could be addressed and further testing would show if usability survey results indicate any significant changes. Also, anecdotal comments on the use of phonetic spelling in the document text could be included in additional usability studies to see which is preferred by patients, the intended audience for the document.

After additional usability studies discussed above, a comparative study could be done on the benefits of the document by studying a random distribution of patients with cancer in a clinical setting. The control group would have the normal experience, while the study group would receive the patient information document. An evaluative survey of patient experience and satisfaction, coupled with the use of anxiety assessments, such as the Profile of Mood States (POMS) and Spielberger's Trait Anxiety Inventory (STAI)) could offer some conclusive evidence of the document's effects in these areas.

After completing further usability and comparative studies, the document could be converted into a more versatile format for publication, such as Adobe InDesign.

Lastly, with a growing numbers of senior citizens, who make up the majority of cancer patients, looking to the Web, some application of the two dimensional information and contents of the document could be formatted so it could be accessed online.

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Appendix A: Patient Information Document

See supplementary pdf -

Appendix A: Cancer Center Patient Manual

Appendix B: Readability Formulas

Formulas below are taken from: *Simply Put: A guide for creating easy-to-understand materials*
A publication of the Centers for Disease Control and Prevention, April, 2009
Page 31

Using SMOG

Perhaps the quickest way to check a reading level manually is to use the SMOG estimating formula. G. Harry McLaughlin created SMOG (Simply Measure of Gobbledygook) in 1969 to estimate they years of education needed to understand a piece of writing.

Here's a quick way to estimate reading level.

- Simply count the number of words with three or more syllables in three chains of 10 sentences in difference parts of your draft.
- Then look up the approximate grade level in this chart.
- The SMOG formula can predict the grade level difficulty within 1.5 grades in 68 percent of passages.

Total Polysyllabic Word Counts	Approximate Grade Level
0-2	4
3-6	5
7-12	6
13-20	7
21-30	8
61-42	9
43-56	10
57-72	11
73-90	12
91-110	college-level

Developed by Harold C. McGraw, Office of Educational Research, Baltimore County Schools, Towson, MD.

McLaughlin worked with programming expert Alain Trottier to produce a free SMOG calculator. The online calculator can service 30 to 2000 words at this link: www.harrymclaughlin.com/SMOG.htm.

Page 32

Using Fry Formula

In 1977, Dr. Edward Fry created one of the most widely used readability formulas. Fry calculates the grade reading level by averaging the number of sentences and syllables per hundred words.

Steps for you to follow:

• Randomly choose three samples from your document with 100 words each.

• Count the number of sentences in the hundred words, estimating length of the fraction of the last sentence to the nearest 1/10th.

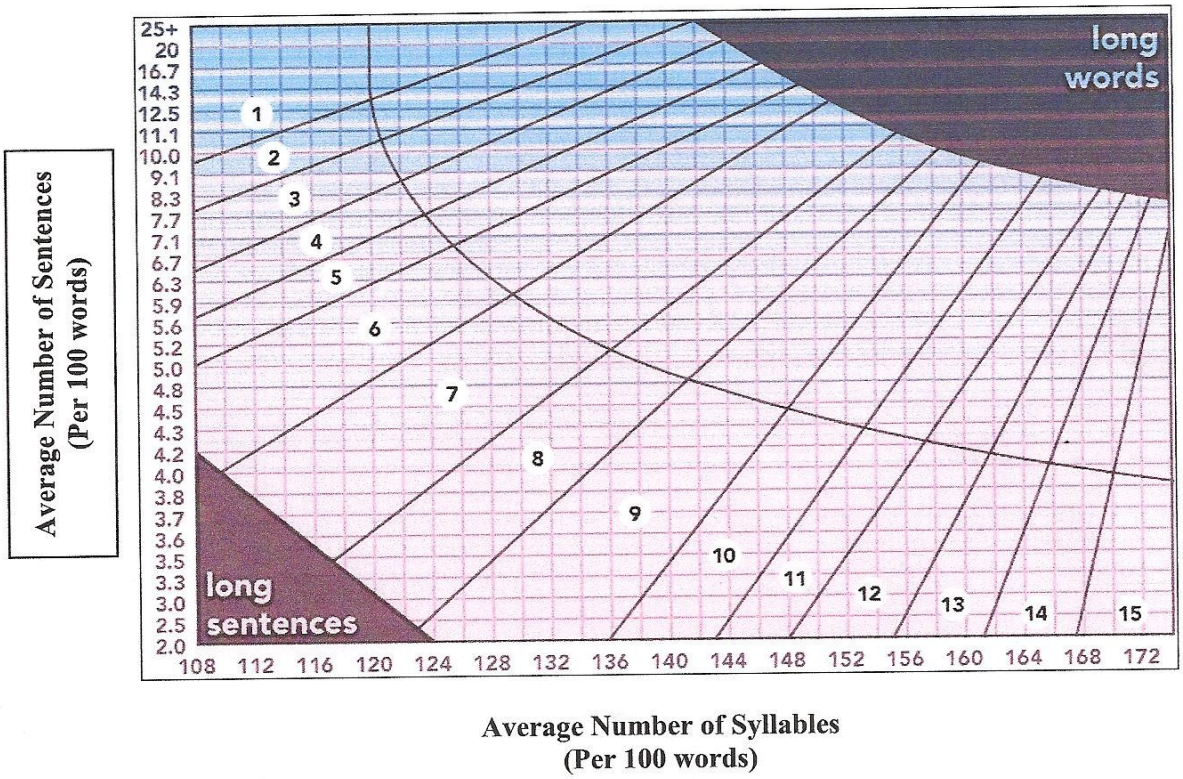
• Count the total number of syllables in the 100-word passage. Do not count numbers. Do count proper nouns. If you don't have a hand counter available, an easy way is to simply put a mark above every syllable after the first syllable in each word. Then, when you get to the end of the passage, count the number of marks and add 100 to include the first syllable in each word that you did not mark.

• Find the average number of sentences and the average number of syllables for the three samples by dividing the total of all three samples by three.

• Use the graph on the next page to plot the average sentence length and number of syllables. The two lines will intersect at the approximate grade level. If a great deal of variability is found, try putting more sample counts into the average

Page 33

Fry Graph* for Estimating Grade Levels



* From: Fry, Edward. Elementary Reading Instruction. 1977, McGraw-Hill

Appendix C: Participant Consent Forms (IRB Approved)

SUBJECT INFORMATION AND INFORMED CONSENT FORM

Project Title:
Production of an Evidence-based Patient Information Document in the form of a Cancer Patient Manual Outlining Cancer Etiology (cause), Treatment and Terminology

Project Director(s):
Student Project Director
Paula McGarvey, Master of Science Candidate
Technical Communication Dept.
Montana Tech of the University of Montana
1301 W. Park St.
Butte, MT 59701
Phone: (406) 490-5460
Email: PJMcgarvey@mtech.edu

Faculty Supervisor
Katherine Eccleston
Writing Instructor & Interim Director of Writing
Technical Communication Department
Montana Tech of the University of Montana
1301 W. Park St.
Butte, MT 59701
Phone: 406 496-4423
Email: keccleston@mtech.edu

Purpose:
The purpose of this survey phase of this project is to recruit cancer patients to evaluate content, design, ease of use and overall usefulness in general of a cancer patient manual prototype.
Research shows that people experiencing a cancer diagnosis experience emotions such as fear and loss of control. Research also shows that health care providers and patients view disease from different perspectives and using different terminology, creating a communication barrier between health care providers and patients.
Input from your survey responses and information you provide about your age, gender, type of cancer diagnosis and type of treatment will be used to determine if the manual prototype succeeded in meeting the needs of cancer patients in these areas.

Procedures:
If you agree to take part in this survey, you will be asked to provide your age, gender, type of cancer diagnosed with, and type of treatment given. You will also be asked to evaluate a cancer patient manual prototype using a survey. The survey will remain anonymous and there will be no way to link your name to your responses. The approximate time for you to complete the survey will be 30 minutes.

Approval Expires On N/A
Date Approved By UM-IRB 10-5-12
IRB-Chair

Benefits and Risks:
Although you may not benefit directly from taking part in this study, the data collected from the survey will be used to refine the cancer patient manual prototype to better serve patients who receive a cancer diagnosis and cancer treatment in the future. Answering the survey and reviewing the information may cause you to think about your own experience being diagnosed and treated for cancer and bring about unpleasant feelings.

Confidentiality:
Your responses will be anonymous. Upon completion of the survey, you will be asked to place it in an envelope and seal it before returning it to the Project Director. Your identity will be kept confidential and in no way linked to the survey questionnaire. Your signed consent form will be stored in a locked cabinet separate from your survey responses.

Voluntary Participation/Withdrawal:
Your decision to take part in this research study is entirely voluntary. You may withdraw from the study at any time, for any reason.

Questions:
If you have any questions about the research now or in the future, you may contact either Project Director Paula McGarvey or Project Supervisor Katherine Eccleston. Contact information is listed above. You may also call the University of Montana Chair of the Institutional Review Board through The University of Montana Research Office at (406) 243-6670.

Approval Expires On N/A
Date Approved By UM-IRB 10-5-12
IRB-Chair

SUBJECT INFORMATION AND INFORMED CONSENT FORM

Project Title:
Production of an Evidence-based Patient Information Document in the form of a Cancer Patient Manual Outlining Cancer Etiology (cause), Treatment and Terminology

Statement of Consent:
I have read the above description of this survey. I have been informed of the risks and benefits involved, and all my questions have been answered to my satisfaction. Furthermore, I have been assured that any future questions I may have will also be answered by a member of the research team. I voluntarily agree to take part in this survey. I understand I will receive a copy of this consent form.

_____
Name of Subject- Print

_____ _____
Name of Subject- Signature Date

Permission to Gather Personal Health Information (PHI) Form

Disclosure of Personal Health Information

My individual health information that may be used to conduct this research includes:

Age
Gender
Type of Cancer I was diagnosed with
Type of cancer treatment I have received

I authorize Paula McGarvey, Montana Tech of the University of Montana master's candidate, to use my individual health information for the purpose of analyzing data collected during a usability study survey for the thesis project entitled "Production of an Evidence-based Patient Information Document in the Form of a Cancer Patient Manual Outlining Cancer Etiology, Treatment and Terminology"

Name: Print_____

Signature_____

Date:_____

Approval Expires On N/A
Date Approved By UM-IRB 10-5-12
IRB-Chair

Appendix D: Survey

Usability Survey

Project: Production of an Evidence-Based Patient Information Document in the form of a Cancer Patient Manual Outlining Cancer Etiology (cause), Treatment and Terminology

Directions: Answer all questions and follow any additional directions given. Circle the response(s) that best apply. Space is provided for additional question specifics and personal comments where applicable.

Section A: Demographic Information

1. **Have you ever been diagnosed with cancer?** (circle one)

   No Stop and return survey to researcher.

   Yes Continue on to questions number 2.

2. **What type of cancer(s) have you been diagnosed with?** (circle all that apply)

   Breast **Lung** **Colon or Colorectal**

   Prostate **Skin** **Other**_____
   (specify)

3. **What type of treatment(s) did you receive?** (circle all that apply)

   Surgery **Chemotherapy** **Radiation Therapy**

   Other_____
   (specify)

4. **What was your age as of January1, 2012?**_____
   (fill in)

5. **Gender** (circle one)

Female **Male**

Section B: Usability Survey

Directions: Take a few minutes to familiarize yourself with the cancer patient manual prototype and its contents before answering the following questions. Space has been provided for any additional comments you would like to make.

1. **This questions concerns your evaluation of the 8 ½ x 11 inch overall size of the manual booklet. In general, how would you rate the size of the manual?** (circle one)

1	2	3	4	5
Poor	Fair	No Opinion	Good	Excellent

Comments?_____

2. **Starting with the front inside cover and using the Table of Contents on page iv. and the tabbed sections as your guide, how would you rate the order in which the information has been presented?** (circle one)

1	2	3	4	5
Poor	Fair	No Opinion	Good	Excellent

Comments?_____

3. Note the tabbed sections corresponding to the Table of Contents on page iv. How would you rate the tabs in regard to ease of finding and accessing information contained in the manual? (circle one)

1	2	3	4	5
Poor	Fair	No opinion	Good	Excellent

Comments?_____

4. Locate Section III: Personalized Treatment Information in the manual prototype.

4a) Rate the ease in which you found the section. (circle one)

1	2	3	4	5
With much difficulty	With some difficulty	No opinion	With some ease	With much ease

Comments?_____

4b) Locate the Personal Treatment Folder and the Question/Appointment Notes Folder included in this section. Pull out inserts included in these folders and replace them. Rate the ease in which you accomplished this task. (circle one)

1	2	3	4	5
With much difficulty	With some difficulty	No opinion	With some ease	With much ease

Comments?_____

Section C: Utility of Manual

1. **Rate the following manual features based on desirability and helpfulness in a manual for cancer patients, according to your own experience(s) as a cancer patient.** (circle one rating number on the right for each feature listed in the left hand column)

	Ratings				
	1	2	3	4	5
Features:	Not at all helpful	Not too helpful	No opinion	Somewhat helpful	Very helpful
Nature Photos	1	2	3	4	5
Contact Information	1	2	3	4	5
Welcome	1	2	3	4	5
Cancer-related Diagrams	1	2	3	4	5
Table of Contents	1	2	3	4	5
Medical Information Photographs	1	2	3	4	5
Explanation of What Cancer is?	1	2	3	4	5
Explanation of Treatments	1	2	3	4	5
Tips for Meeting with Healthcare Providers	1	2	3	4	5

Ratings

Features:	1 Not at all helpful	2 Not too helpful	3 No opinion	4 Somewhat helpful	5 Very helpful
Personalized Treatment Folder	1	2	3	4	5
Commonly Asked Questions List	1	2	3	4	5
Personal Question/ Appointment Note Folder	1	2	3	4	5
Healthcare Provider Job Descriptions	1	2	3	4	5
Personal Resource List	1	2	3	4	5
Local/On-line Resource Folder	1	2	3	4	5
Glossary of Cancer Terms	1	2	3	4	5
References	1	2	3	4	5
Inspirational Quotes	1	2	3	4	5
Cancer-related Poetry	1	2	3	4	5

Comments?_____

_____

Make sure all questions have been answered. Place survey in the envelope provided, seal and return to researcher. Thank vou.

Appendix E: Recruitment Publication Request

Paula J. McGarvey
Master's Candidate Technical Communication
Montana Tech of the University of Montana
1301 W. Park St.
Butte, MT 59701

Gerry O'Brien, Editor and/or
Carmen Winslow, Associate Editor
The Montana Standard
25 W. Granite St.
Butte, MT 59701

Current Date

Dear Editors,

Would you please include the following item in the Southwest Montana Snapshots section of *The Montana Standard*? I would appreciate it if you could run it several times over the next few weeks.

Cancer survivors needed for survey

Paula McGarvey, a graduate student at Montana Tech of the University of Montana, is looking for volunteers age 18 and older who have been diagnosed with cancer. Volunteers must be willing to help evaluate a cancer patient manual prototype and participate in a survey—the results of which, will be used in the completion of her Master's Thesis Project in Technical Communication.

Volunteers will be asked to schedule an appointment to meet with McGarvey to review the manual prototype. Appointments will take approximately 30 minutes. Participants will be asked to sign both consent and personal health information release forms. Surveys will remain anonymous and will request information about age, gender, type of cancer diagnosed with, type of treatment received and evaluation questions concerning the manual prototype. McGarvey's inspiration for this project stems from her own personal experience as cancer patient in 2007 and 2011 and a strong desire to improve the cancer patient's health care experience by providing disease and treatment-related information and education. For more information, call McGarvey at 782-6510 or 490-5460, or Email at PJMcgarvey@mtech.edu.

Thank you very much for your help with this project.

Sincerely,
Paula J. McGarvey

Approval Expires On N/A
Date Approved By UM-IRB 10-5-12
IRB-Chair

Appendix F: IRB Approval and NIH Certificate

Form RA-108
(Rev. 11/11)

THE UNIVERSITY OF MONTANA-MISSOULA
Institutional Review Board (IRB)
for the Protection of Human Subjects in Research
CHECKLIST / APPLICATION

IRB Protocol No.: 160-12

At The University of Montana (UM), the Institutional Review Board (IRB) is the institutional review body responsible for oversight of all research activities involving human subjects outlined in the U.S. Department of Health and Human Services Office of Human Research Protection (www.hhs.gov/ohrp) and the National Institutes of Health, Inclusion of Children Policy Implementation (http://grants.nih.gov/grants/funding/children/children.htm).

Instructions: A separate application form must be submitted for each project. IRB proposals are approved for no longer than one year and must be continued annually. Faculty and students may email the completed form as a Word document to IRB@umontana.edu. or submit a hardcopy to the Office of the Vice President for Research & Development, University Hall 116. Student applications must be accompanied by email authorization by the supervising faculty member or a signed hard copy. *All fields must be completed. If an item does not apply to this project, write in: n/a.*

1. Administrative Information

Project Title: Production of a Evidence-based Patient Information Document in the Form of a Cancer Patient Manual Outlining Cancer Etiology, Treatment and Terminology	
Principal Investigator: Paula J. McGarvey	Title: Master of Science Candidate Technical Communication
Email address: PJMcgarvey@mtech.edu AND paulajmc@bresnan.net	
Work Phone: (406) 782-6510	Cell Phone: (406) 490-5460
Department: MT TECH Professional and Technical Communication	Office location: ENG 205

2. Human Subjects Protection Training

(All researchers, including faculty supervisors for student projects, must have completed a self-study course on protection of human research subjects ***within the last three years*** *(http://www.umt.edu/research/complianceinfo/IRB/) and be able to supply the "Certificate(s) of Completion" upon request. Add rows to table if needed.*

NAME and DEPT.	PI	CO-PI	Faculty Supervisor	Research Assistant	DATE COMPLETED Human Subjects Protection Course
Paula J. McGarvey, MSTC Candidate Technical Communication Dept. Montana Tech of the University of Montana	☒	☐	☐	☐	8/28/2012 (certificate # 840023)
Katherine Eccleston Writing Instructor I & Interim Director of Writing Technical Communication Dept. Montana Tech of the University of Montana	☐	☐	☒	☐	04/12/2012 (certificate # 429828)

3. Project Funding

(If federally funded, you must submit a copy of the abstract.)

Is grant application currently under review at a grant funding agency? ☐Yes *(If yes, cite sponsor on ICF if applicable)* ☒No		Has grant proposal received approval and funding? ☐Yes *(If yes, cite sponsor on ICF if applicable)* ☒No		
Agency	Grant No.	Start Date	End Date	PI
Is this part of a thesis or dissertation? ☐No ☒Yes		If yes, whose? Paula J. McGarvey		

For UM-IRB Use Only

IRB Determination:

_____ Not Human Subjects Research
_✓_ Approved Exempt from Review, Exemption # _2_ *(see memo)*
_____ Approved by Expedited Review, Category #____ *(see* ***Note to PI****)*
_____ Full IRB Determination
_____ Approved *(see* ***Note to PI****)*
_____ Conditional Approval *(see memo)* - IRB Chair Signature/Date: _____
_____ Conditions Met *(see* ***Note to PI****)*
_____ Resubmit Proposal *(see memo)*
_____ Disapproved *(see memo)*

Risk Level: Minimal

*** Note to PI:** Study is approved for one year. Use any attached IRB-approved forms (signed/dated) as "masters" when preparing copies. If continuing beyond the expiration date, a continuation report must be submitted. Notify the IRB if any significant changes or unanticipated events occur. Notify the IRB in writing when the study is terminated

Final Approval by IRB Chair/Coordinator: _____ Date: 10-5-12 Expires: N/A

The University of Montana

INSTITUTIONAL REVIEW BOARD
for the Protection of Human Subjects in Research
FWA 00000078

Research & Creative Scholarship
University Hall 116
The University of Montana
Missoula, MT 59812
Phone 406-243-6672 | Fax 406-243-6330

Date: October 5, 2012

To: Paula J. McGarvey, Technical Communication, MTech

From: ☒ Paula Baker, IRB Coordinator
☐ Dan Corti, IRB Chair

RE: IRB 160-12: "Production of a Evidence-based Patient Information Document in the Form of a Cancer Patient Manual Outlining Cancer Etiology, Treatment and Terminology"

Your IRB proposal cited above has been **approved** under the **Exempt** category of review by the Institutional Review Board in accordance with the Code of Federal Regulations, Part 46, section 101. The specific paragraph which applies to your research is:

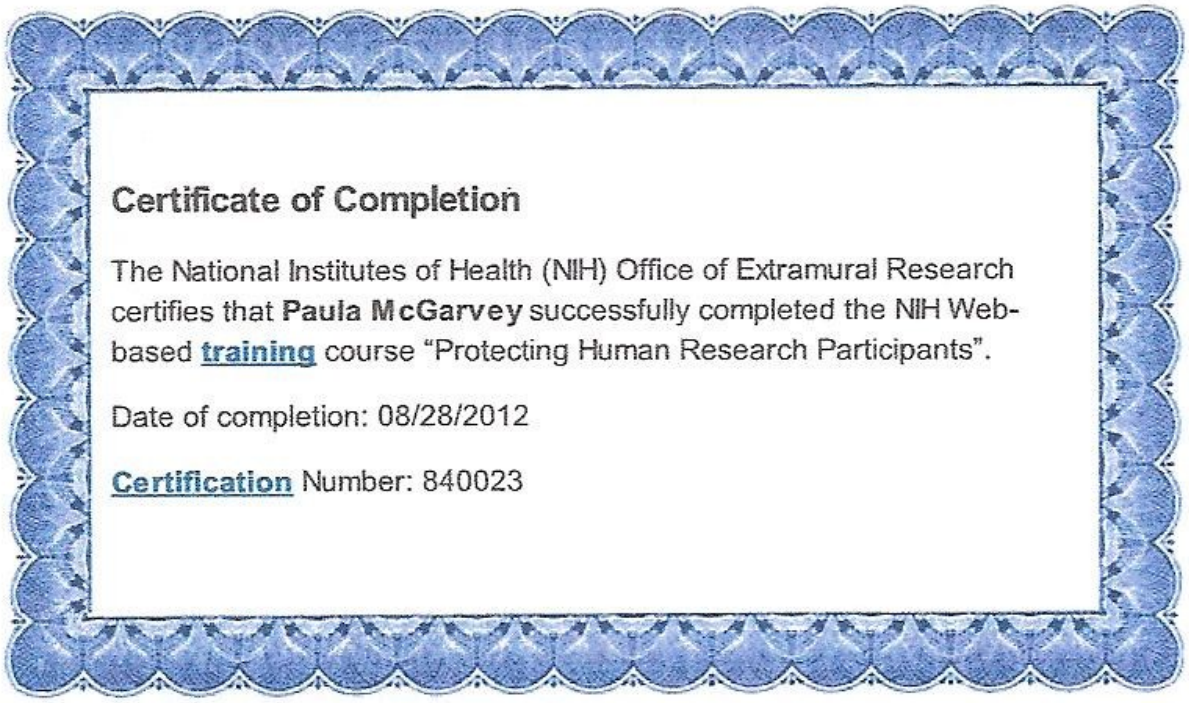
_X_ (b)(2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless: (i) Information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

University of Montana IRB policy does not require you to file an annual Continuation Report for exempt studies as there is no expiration date on the approval. However, you are required to notify the IRB of the following:

Amendments: Any changes to the originally-approved protocol must be reviewed and approved by the IRB ***before*** being made (unless extremely minor). Requests must be submitted using Form RA-110.

Unanticipated or Adverse Events: You are required to timely notify the IRB if any unanticipated or adverse events occur during the study, if you experience an increased risk to the participants, or if you have participants withdraw from the study or register complaints about the study. Use Form RA-111.

Please contact the IRB office with any questions at (406) 243-6672 or email irb@umontana.edu.



Certificate of Completion

The National Institutes of Health (NIH) Office of Extramural Research certifies that **Paula McGarvey** successfully completed the NIH Web-based **training** course "Protecting Human Research Participants".

Date of completion: 08/28/2012

Certification Number: 840023

SIGNATURE PAGE

This is to certify that the thesis prepared by Paula J. McGarvey entitled "Production of an Evidence-based Patient Information Document in the form of a Cancer Patient Manual Outlining Cancer Etiology, Treatment, and Terminology" has been examined and approved for acceptance by the Department of Technical Communication, Montana Tech of The University of Montana, on this 6th day of December, 2012.

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