MANAGEMENT OF TECHNOLOGY

MEDICAL INFORMATION SOURCES FOR CANCER PATIENTS AND THEIR COMPANIONS

CHEN WANG

Thesis under the direction of Professor David M. Dilts

Today patients and their companions use various sources to gain knowledge of cancer. The ability to clearly determine their current and future information sources can help both physicians and patients to better communicate and make more efficient decisions together, but limited studies have done for this. A survey was implemented in the oncology clinic of the Vanderbilt Ingram Cancer Center, Nashville, TN. Of the 468 individuals approached, 424 (91%; 257 patients and 167 companions) completed the questionnaires, with 166 patients paired with companions. Over 95% believed information enhanced their involvement in decision making and abilities to cope with cancer; 77% reported that information reduced anxiety. 85% will continue to search for cancer information in the future. Physicians, nurses, and medical pamphlets are still the most trusted sources. Internet and email were not used as much as expected but showed more potential uses and better quality in the future. Demographics including education, income, gender, age and working status are found as good predictors for cancer information source preferences. Future research is needed on physicians' views on cancer patients' medical information sources.

MEDICAL INFORMATION SOURCES
FOR CANCER PATIENTS AND THEIR COMPANIONS

By

Chen Wang

Thesis

Submitted to the Faculty of the

Graduate School of Vanderbilt University

in partial fulfillment of the requirements

for the degree of

MASTER OF SCIENCE

in

Management of Technology

May, 2005

Nashville, Tennessee

Approved:

David M. Dilts

Barbara Murphy

In memory of my father, the most influential in my life

To my mother, infinitely supportive all the time

and

To my beloved one, Yong, known since life before life

ACKNOWLEDGMENTS

Doing research for this thesis is a process of growing up all over again, with gifts including patience, persistence, a pair of eyes with broader views of knowledge, a mind with more thoughts towards life, and a heart with more appreciations for others.

I must thank Dr. David Dilts: you guided me into the research world where I was often pleasantly surprised. You generously shared your knowledge, experience, and your serious attitude toward research. You were strict in class but really nice in life.

I must thank Dr. Barbara Murphy: without your great help I could not imagine how hard it would be. Your advices were always beneficial, and your considerateness always made me feel at home. You are not only a professional, a mentor, but also a friend.

I am grateful to all the staff in the cancer clinic of the Vanderbilt Ingram Cancer Center, especially Kevin, Elisa, Michael, Debra, Linda, Dr. Johnson, Dr. Roth, Dr. Carbon, Dr. Sandler, Dr. Rothenberg, Dr. Sosman, and Dr. Moots, for your valuable time and help.

I hope I could express my appreciation in person to those cancer patients and companions who participated in this research: your selfless willingness to contribute while struggling with disease touched me over and over again. Being with you, I felt powered.

I would like to thank Mary Jane: you were always ready to help since the very first day I came here, especially during those hard times that I had for both study and life.

I would also like to thank Bin: you were always willing to share your innovative ideas and inspiring suggestions which usually made me feel suddenly enlightened.

Finally, I would like to thank all my good friends in MOT program, Yu, Gouri, Pedro, Sid, Max, Autumn, and Kisha: I will treasure our shared memories forever.

TABLE OF CONTENTS

Page

Chapter

Appendix

LIST OF TABLES

LIST OF FIGURES

Figure **Page**

CHAPTER I

INTRODUCTION

During the last two decades, it has become usual that patients play a more active and autonomous role (Kleffens, et al, 2003). Unlike many patients of the past, today's health-care users want to become more informed about their illnesses (Satterlund et al, 2003). Increasingly acting as independent learners, patients are facing a wider range of information resources, including patients with cancer (National Cancer Alliance, 1996).

Cancer is a serious human health issue (Junghans et al, 2004), which is the second leading cause of death in the US, exceeded only by heart disease, and causes 1 of every 4 death (ACS, 2004a). The National Cancer Institute estimates that more than 18 million new cancer cases have been diagnosed since 1990 and about 1,368,030 are expected to be diagnosed in 2004 (ACS, 2004a). Half of all men and one-third of all women in the US will develop cancer during their lifetimes (ACS, 2004b). Today, millions of people are living with cancer or have had cancer (ACS, 2004b), who are experiencing or have experienced uncertainty, fear, and loss that are invoked by the diagnosis of cancer and can be alleviated by communication and information (Butow et al, 1994; Fallowfield et al, 1990; Houts et al, 1991).

Communication and information, over recent years, have increasingly been considered important in helping people to cope with cancer (Leydon et al, 2000). Research has indicated that the vast majority of cancer patients want to be informed about their illness (Meredith et al, 1996). Appropriate information, offered at the right time, has been recognized as a key factor in enabling patients to cope with a diagnosis of cancer (Mills and Davidson, 2002). Therefore, understanding what patients need to know, when during the course of care, and from whom they receive this information becomes vital to ensuring the delivery of quality cancer care (Rutten et al, 2004).

In the past, consumers sought information mainly from health professionals (Carlson, 2000; Satterlund et al, 2003). Today, patients use various sources of health information to gain knowledge about their illness and prognosis, treatment options and side effects, ways to prevent recurrence, and psychological resources for coping (Cassileth et al, 1980; Fallowfield et al, 1994). So do their companions. The ability to clearly determine patients' and their companions' potential medical information sources can help both physicians and patients to make more efficient communications and decisions together (Dranove, 1988; Labelle et al, 1994; Kleffens et al, 2003; Basch et al, 2004).

Factors that may influence patients' information seeking preferences include the time from diagnosis, age, gender, education, type of cancer, treatment and stage of disease (Derdiarian, 1987; Mills and Davidson, 2002). However, there is considerable disagreement as to the influence of some of these variables in information seeking behavior (Mills et at, 2002), as mentioned in their study that: "Given the conflicting conclusions in the literature it is important to clarify the relationship between Sociodemographic and disease variables and information seeking behavior." And it is not clear as to whether patients and their companions differ in their patterns of content seeking (Basch et al, 2004).

All these have addressed the importance of patients' and their companions' preferences of medical information sources and their obtained medical information level. However, for cancer, which is one of the most important diseases in the US (ACS, 2004b), little has been done in this field.

Current Studies for Medical Information Sources

Many studies about patient information sources have been done for diseases like heart failure (Gwadry-Sridhar et al, 2003) and AIDS (Reeves, 2000; Buseh et al, 2002). Some studies have examined sources of information related to breast cancer (Rees and Bath, 2000b), with specific attention to mass media (Johnson and Meischke, 1991a; Gottlieb, 2001; Rees and Bath, 2000a). However, despite the extensive literature on information provision for patients with cancer, there are only a limited number of studies that have investigated the preferred sources of information for cancer patients (Mills and Davidson, 2002).

Among these limited number of studies, most were done in Europe, such as UK (Fallowfield et al, 1995; Hardwick and Lawson, 1995; James et al, 1999; Mossman et al, 1999), Sweden (Carlson, 2000), Ireland (Mills and Davidson, 2002), and Holland (Kleffens et al, 2003). Some were also done in Canada, including Pereira et al (2000), Chen and Siu (2001), Champman and Rush (2003). However, less has been done in US concerning patient preferred sources of information despite several publications focusing on the quality of Internet health care content (Basch et al, 2004).

There are only two similar studies accomplished recently in US, which were accomplished respectively by Kakai et al (2003) and Basch et al (2004). Kakai et al (2003) examined patterns in the use of health information among Caucasian, Japanese, and non-Japanese Asian Pacific Islander cancer patients in Hawaii, but the study has a selection bias which may limit the generalizability. And Basch et al (2004) implemented a survey studying how cancer patients and their companions used information resources, but it focused more on the comparison between electronic and nonelectronic resources than an overall analysis, and it didn't ask what information sources cancer patients and their companions would potentially use in the future.

Taking one with another, few surveys asked the patients about the quality of such cancer information sources they went, especially the quality of print products used by patients (Basch et al, 2004). Moreover, there is almost no survey asked patients and their companions about the potential information sources they will go in the future, let alone their expected quality of those potential information sources.

Therefore, it is important for the present study to find out patients and their companions past and future medical information source preferences with their assessment of the information quality, and to test whether patient demographics can be used as a predictor for their medical information source preferences, both of which lie in the stream of information seeking research.

Thesis Objectives

The study of information seeking behavior can be defined as concerning itself with finding out "what kind of people seek kinds of information through what channels" (Parker and Paisley, 1966). Understanding *who* searches for information, *why* they search for information (*importance*), *what* they need to know (*topic*), *when* during the course of care (*stage*), and *where* they receive information (*source*) becomes vital to ensuring the delivery of quality care (Rutten et al, 2004) and to making informed decisions (Labelle et al 1994; Kleffens et al 2003; Basch et al, 2004).

Therefore, the objectives of the present study are to: 1) investigate *who* searches for the information about cancer (patient and companion), and compare their medical information seeking behavior; 2) investigate *why* they searches for such information, that is, what benefits they believe they can get from such information; 3) investigate *what* their information needs are by cancer stage (e.g., whether there is similarity between topics searched in the same stage of cancer or whether there is difference between topics searched in different stages of cancer); 4) investigate *where* they go or will go for these information in the past and in the future; and 5) investigate whether demographics can be used as a *predictor* for patient's or companion's medical information source preferences; 6) investigate the information *quality* assessed or expected by cancer patients and their companions for current sources, and the impact of the quality assessment on their future source uses.

A survey was implemented in the Oncology clinic of the Vanderbilt Ingram Cancer Center (VICC), with the approval from the Center and the Institutional Review Board (IRB) at Vanderbilt University. There are three parts in this survey: Part A and Part B. Part A investigates demographic information. Part B has three sections: Section B1 investigates participants' medical information sources in the past and potential medical information sources in the future; Section B2 investigates specific medical topics that participants searched in the past and will search in the future; Section B3 investigates specific websites that participants visited in the past and will visit in the future. Patients were recruited on a daily basis to complete all the questions of the survey questionnaire. Multivariate Analysis Tests, including Analysis of Variance (ANOVA) and Multivariate Analysis of Variance (MANOVA), were used as the statistics tools to analyze the data collected.

This paper is organized in six sections. This is the first section, which is a brief introduction to the study. The second section examines the theories and concepts of medical information sources, patient demography, and the relationship between the two through a literature review. The primary purpose of this section is to build a rationale and theoretical basis for defining and categorizing "information seeking behavior", "information sources", and "relationship between demography and information sources" with respect to medical field and especially to cancer patients. The third section develops a research model, the hypotheses, and then the measurement instruments with a further literature review. The hypotheses are investigated using a survey methodology that is described in details in the fourth section. The fifth section statistically analyzes the data and finally reaches and discusses the results. The sixth section, the discussing and concluding section delineates the implications both for practice and research, the potential limitations of the present study, and the directions for future research.

CHAPTER II

LITERATURE REVIEW

Today, patients use various sources to gain knowledge about their illness (Fallowfield et al, 1994). So do their companions, i.e., the “informal care-givers” who share and affect patients’ experiences (Basch et al, 2004; Thomas et al, 2002). Understanding *who* searches for information, *why* they search for information (*importance*), *what* they need to know (*topic*), *when* during the course of care (*stage*), and *where* they receive information (*source*) becomes vital to ensuring the delivery of quality care (Rutten et al, 2004) and to making informed decisions (Labelle et al 1994; Kleffens et al 2003; Basch et al, 2004). Therefore, it is important to clarify the relationship between socio-demographic (*predictor*) and medical information searching, that is, to discover “who” is searching and how they structure their source horizon (Mills and Davidson, 2002). It is also important to highlight the *information quality* patients and companions get from these sources (Mills and Davidson, 2002; Satterlund et al, 2003), since judgments drawn from the previous experiences have an impact on the future use of information sources (Hertzum et al, 2002).

Thus, this literature review is divided into 6 sections: 1) patient’s and companion’s medical information seeking behavior (*who*); 2) importance of information for cancer patients and companions (*why*); 3) medical information needs by stage (*what* and *when*); 4) medical information source preferences (*where*); 5) demographics (*predictor*) and medical information source horizon; and 6) quality of patient obtained medical information (POMI) and companion obtained medical information (COMI) (*information quality*).

Patients’ and Companions’ Information Seeking Behavior

It has long been recognized by medical sociologists and other health researchers that patients’ illness experiences cannot be understood as individualized, socially isolated phenomena (Anderson and Bury, 1988; Bury 1991 and 1997; Kelly and Field, 1996; Thomas et al, 2002). Spouses, partners, other family members, and close friends actively participate in shaping the patients’ illness experience and share in this experience; especially, spousal carers often symbolically share in the illness and present the struggle with cancer as a joint one (Thomas et al, 2002). The practical involvement of these socially significant others in patients’ journeys through illness affects these companions’ own lives, sometimes in profound ways (Anderson and Bury, 1988; Thomas et al, 2002). Particularly if they actively “look after” people with chronic illnesses and long standing impairments, they are now commonly referred to as “informal carers” (Thomas, 1993; Heaton, 1999).

Such “informal carers” also make sense with cancer. Although the enduring cultural image of cancer is of an acute and deadly disease that acts swiftly to end life, and from this point view the care role is one of short duration, the reality of cancer is otherwise (Thomas et al, 2002). Whilst it is the case that cancer mortality rates remain obstinately high in industrial countries, cancers are now seen within medicine as a disease with very variable rates of cure (WHO, 1998; Thomas et al, 2002). The duration of periods in which illness symptoms are experienced, and actively treated, is therefore variable for different types of tumors, and may last for years. There are increasing numbers of people in the population who no longer experience illness symptoms but are in remission rather than “cured” of cancer (Frank, 1995). This means that, once diagnosed, cancer patients often carry their “patienthood” status for long periods of time; and during such a long period of time, there are likely to be times that cancer patients need informal care-giving and emotional support (Thomas et al, 2002), especially in the final stage.

Therefore, cancer is a family-impacted disease (Mystakidou et al, 2002). The family system has a note-worthy "family culture", whose aspects of values and behaviors are the key variables, along with life experiences, socio-economic status, and personality differences, that affect the meaning of cancer for both individuals and their families (Gotay, 1996; Germino et al, 1998; Juarez et al, 1999; Mystakidou et al, 2002). Thus, it is important to mention the close bonds found in a family, especially towards severe problems such as cancer (Mystakidou et al, 2002). That is the reason why cancer patients' information seeking behavior cannot be isolated from their companions' participation, which has been demonstrated by several studies (Borgers et al, 1993; Basch et al, 2004).

Borgers et al (1993) measured cancer patients' intention to seek information, their realization of the intention and the reasons for not realizing it through questionnaires and focus group interviews. They found that in 22% of cases cancer outpatients do not realize their intention, and in 25% of cases the realization of the intention is due to the initiative of the specialist or the patient's companion. They concluded that the information seeking behavior of cancer outpatients appears to be influenced by several factors, including patients' needs, values and beliefs, and specialists' and companions' behavior.

It has also been found that there was a high rate of concordance between patient's and companion's information seeking behavior (Basch et al 2004). Basch et al made a survey to evaluate the resource use of patients and their companions, and they noted that for each resource type and for resource use overall, companions whose patient counterparts denied use were more likely to report use than were patients whose companions denied use.

Therefore, the health care team-patient relationship is a triangle not a dyad, consisting of the health care professionals, the patient and the family (Mystakidou et al, 2002). Each part supports the relationship between the other two, and each is affected by what else happens in the triangle. Hence, the involvement of health care team and companions is very important for the care and treatment of the patients (Blanchard et al, 1996; Humphrey et al, 1992).

However, although several researchers have analyzed influences from companions to cancer patients during medical information seeking (Thomas et al, 2002; Mystakidou et al, 2002; Blanchard et al, 1996; Humphrey et al, 1992), few studies have compared cancer patients' and their companions' information needs and source preferences (Basch et al, 2004). It is unknown if there is a significant interrelationship between cancer patients and their companions in information searching and information sources for medical information. Therefore, we will make a comparison between cancer patients and their companions for each hypothesis developed in the following sections, with HP standing for Hypothesis for Patients and HC standing for Hypothesis Companions.

Importance of Information for Cancer Patients

"Medical information" is defined as "information or data, whether oral or recorded, in any form or medium, created by or derived from a health care provider or the consumer, that relates to the past, present, or future physical, mental, or behavioral health or condition of an individual, the provision of health care to an individual, or the payment for the provision of health care to an individual" (FACTA, 2003). There are usually two situations for patient obtained medical information (POMI): on one hand, sufficient and appropriate medical information that contributes to better-quality decisions and perhaps improves health outcomes (Jefford and Tattersall, 2002);

and on the other hand, lack of or inadequate information that negatively influences patients' treatment decisions (Beaver et al, 1999).

Studies show that lack of information can cause dissatisfaction, reduction in patient wellbeing, distress in patients and their families (Fallowfield et al, 1990), but also can lead to increased uncertainty, anxiety, distress, dissatisfaction, and can negatively influence patients' treatment decisions (Beaver et al, 1999). Failure to provide sufficient information about illness and treatment is the most frequent source of patient dissatisfaction (Grol et al, 2000; Coulter and Cleary, 2001). Additionally, patients who are well-informed about prognosis and treatment options are more likely to adhere to treatments (Marinker et al, 1997), while patients who believed that they had received inadequate information were more likely to pursue alternative therapies (Pruyn et al, 1985).

Today's health-care users want to become more informed about their illnesses (Satterlund et al, 2003), with the intention to reduce uncertainty by accessing information that can lead to decision-making control over information flow, and higher quality of life (Laine and Davidoff, 1996; Kaplan et al, 1996; McCreadie and Rice, 1999; Coulter, 2003). This is because medical information has many functions for patients (See Table 1): 1) information can help patients to gain control, to promote self-care and participation, and to increase their involvement in decision-making (Luker et al, 1995; Cawley et al, 1990; Rutten et al, 2004; Mills and Sullivan, 1999; Jefford and Tattersall, 2002); 2) the information from various sources can also provide patients with knowledge, advice, and support for treatments and treatment decisions, and thus make patients more satisfied with treatment choices (Luker et al, 1995; Cawley et al, 1990; Rutten et al, 2004); 3) information can improve patients' abilities to cope during the diagnosis, treatment, and post-treatment phases (Cassileth, 1980; Fallowfield et al, 1995; Coulter, 1995; Ford et al, 1995;

Meredith et al, 1996; Harrison-Woermke and Graydon, 1993; Damian and Tattersall, 1991; Johnson et al, 1988; Rutten et al, 2004); 4) information can also help to reduce anxiety, alleviate the uncertainty, fear, and loss invoked by a diagnosis of cancer and generate feelings of safety and security (Rainey, 1985; Mills and Sullivan, 1999; Fallowfield et al, 1990; Houts et al, 1991; Meredith et al, 1996; Butow et al, 1994; Rutten et al, 2004); 5) finally, information can improve communication with family members (Rutten et al, 2004). Therefore, access to appropriately tailored medical information have increasingly been considered important in helping patients to cope with cancer (Fallowfield, 1989; Johnson and Adelstein, 1991; Reynolds et al, 1998; Hogben and Rutten et al, 2004).

Table 1: Information Benefits for Cancer Patients

Information Benefits	Citation List
Increase involvement in decision making	Luker et al (1995), Rutten et al (2004), Cawley et al (1990), Mills and Sullivan (1999), Jefford and Tattersall (2002)
More satisfaction with treatment choices	Luker et al (1995), Cawley et al (1990), Rutten et al (2004)
Reduce anxiety/generate feelings of safety/security	Rainey (1985), Mills and Sullivan (1999), Fallowfield et al (1990), Houts et al (1991), Meredith et al (1996), Butow et al (1994), Rutten et al (2004)
Increase ability to cope with cancer	Cassileth (1980), Fallowfield et al (1995), Coulter (1995), Ford et al (1995), Meredith et al (1996), Harrison-Woermke and Graydon (1993), Damian and Tattersall (1991), Johnson et al (1988), Rutten et al (2004)
Improve communication with families	Fallowfield (1989), Johnson and Adelstein (1991), Reynolds et al (1998), Hogben and Rutten et al (2004)

However, few surveys asked cancer patients and companions about their experiences with information benefits (Rutten et al, 2004). This is the basis of the following hypotheses:

H1P: Cancer patients believe that information is beneficial for them to cope with cancer.

H1Pa: Cancer patients believe that information increases their involvement in decision-making.

H1Pb: Cancer patients believe that information increases their satisfaction with treatment choices.

H1Pc: Cancer patients believe that information improves their ability to cope during the diagnosis, treatment, and post-treatment phases.

H1Pd: Cancer patients believe that information reduces their anxiety.

H1Pe: Cancer patients believe that information improves the communication among family members.

H1C: Companions have the same beliefs as their paired patients about information benefits.

Medical Information Needs By Stage

As information has the above-mentioned functions (Mills and Sullivan, 1999) that are beneficial to cope with the disease, cancer patients have a great need of information. In a survey which investigates the supportive care needs of newly diagnosed patients with cancer in Canada, Whelan et al (1997) reported that 85% of patients had informational needs. Therefore, it is very important to take into account patients' and companions' needs for information and also their level of desire for medical information (Turk et al, 1997).

The investigation of information needs in relation to health problems and health information services has been investigated by numerous researchers in the health disciplines (For a review see Johnson, 2003). Johnson and Meischke (1991b) note that (in terms of seeking information related to cancer), an individual may be looking for factual information about prevention, detection and treatment, or for information that will enable him or her to deal with the problem emotionally (Johnson, 2003). What is more, Carter (reported in Chew, 1994) suggests that when an individual is driven to seek information as a result of "needing to know", they usually want to "discover what is happening" (orientation), "check that the person is on the right track" (reorientation), and "form an opinion or solve a problem" (construction), i.e., different information types by stage.

This is supported in cancer field by a literature review of the information needs of patients with cancer and their families, in which Harris (1998) reports that the National Cancer Institute's Office of Cancer Communications reviewed the literature published from 1979 to 1990 covering information, education and communication. One of the key findings was: patients with cancer want information about what would happen to them in the immediate future cancer-specific information (e.g., treatment-related information, 38.1%; prognosis information 10.8%, Rutten et al, 2004). Other studies also reported that patients with cancer and their caregivers seek information about their diagnosis and prognosis, conventional and alternative therapeutic options, risks and benefits of treatment, and relevant experimental therapies (Cassileth et al, 1980; Champman and Rush, 2003; Coulter, 2003; Hardwick and Lawson, 1995; Manfredi et al, 1993; Basch et al, 2004). Moreover, several studies found that patients wanted all possible information they could get. In a recent study of 2331 patients with different types of cancer, 98% said they wanted all possible information (Jenkins et al, 2001). Other researchers from the UK and USA have suggested that the great majority of patients wish to receive as much information as possible (Blanchard et al, 1988). Likewise, situations are similar for companions: since cancer is a family-impacted disease, companions need to adjust to the new life situation to support the patient and to share the burden of the illness, they also need to receive relevant information and emotional support (Eriksson and Lauri, 2000).

However, not all patients or companions want information at all stages of their illness, and it is recognized that patients vary in how much information they want during different stages (Leydon et al, 2000). Johnson (1993b) and Johnson and Meischke (1993) found that, in the early stages of cancer-related information seeking, when someone is not confronted with the symptoms or disease, but may be mildly concerned with prevention, it does not appear that antecedents and characteristics are linked in any meaningful way (Johnson and Meischke, 1993). In later stages, when confronted with symptoms or disease, for most individuals, searching for cancer-related information is a non-recurring problem, which is novel and fraught with emotional complications (Johnson, 1996).

Therefore, cancer patients have different information needs in different cancer stages, and thus they will seek for different medical topics during different stages accordingly. However, there are few surveys concerning the relation between these two (Satterlund et al, 2003). It is unknown if cancer patients search for certain topics during certain stages of their disease experiences. This is the basis for the following hypotheses:

H2P: There is a significant relationship between stages of cancer disease and types of medical topics searched by cancer patients.

H2Pa: Cancer patients search for different medical topics in different stages.

H2Pb: Cancer patients in the same stage search for similar medical information.

H2C: Companions search for same topics as cancer patients through different stages.

Medical Information Source Preferences

As mentioned at the beginning of this literature review, understanding *who* searches for information, *why* they search for information (*importance*), *what* they need to know (*topic*), *when* during the course of care (*stage*), and *where* they receive information (*source*) becomes vital to ensuring the delivery of quality cancer care. Having discussed the *what*, *why*, and *when* in previous sections, we will focus on *where* (*source*) in this section.

It becomes important to know where cancer patients went for Patient Obtained Medical Information (POMI) in the past, and might go in the future, since information source preferences have a strong impact on patients' decision-making (van Kleffens et al, 2003). For example, Chen and Siu (2001) noted in their survey that, with preference to other information sources rather than physicians, 29.4% of patients requested specific treatments, and 6.3% of patients declined treatments recommended by their oncologists. This result is in agreement with the report by Pew Internet and American Life Project: among those who have searched for medical information online, 70% said that the information influenced their opinion on how an illness should be treated, 50% said that the information led them to ask their doctors new questions or obtain a second opinion, and 28% said that the information affected their decision of whether to visit a doctor or not (Pew, 2001).

For another example, Conesa et al's (2004) survey on organ donation decision found that: since TV is the medium with the greatest incidence on the population, the increases in donation refusal that are noted from time to time go hand in hand with negative news on TV about organ donors and transplants; and there may even be an overflow effect – some studies have shown that campaigns to promote organ donation have led to increases in negative opinions (Verble and Worth, 1996).

Therefore, in this section, we will introduce: 1) *Media Richness Model* to help explain why there exist choices or preferences for information sources (Daft et al, 1987; Ambra and Rice, 1994); and 2) *Information Source Horizon* to help show how these choices or preferences can be structured (Savolainen et al, 2004).

Media Richness Model

Information sources can be both broad (e.g., society or institutions that generate information messages) and narrow (e.g., a doctor communicating health information to a patient) (Spink and Cole, 2001). These communication media differ in their ability to facilitate understanding - they can be characterized as high or low in "richness" based on their capacity to facilitate shared meaning (Daft et al, 1987) with the following rankings: 1) face-to-face, 2) telephone, 3) addressed documents, and 4) unaddressed documents (See Figure). For example, face-to-face communication is richer (can better facilitate changes in understanding) than writing memos because it enables immediate feedback and the conveyance of cues such as facial expressions (Kahai and Cooper, 2003).

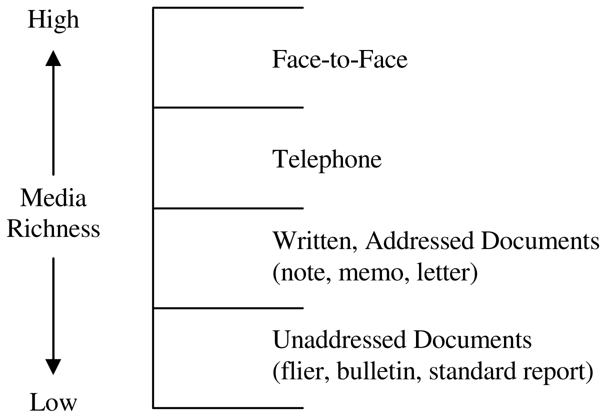


Figure 1: Hierarchy of Media Richness source: Daft et al (1987)

However, although the model has performed reasonably well with traditional media (e.g., face-to-face, telephone, and written memos), there are many findings that it cannot explain when newer media (e.g., e-mail and video) are included (Kahai and Cooper, 2003; Carlson and Zmud, 1999; Fulk and Byod, 1991; Rice and Shook, 1990; Rice et al, 1998). Recent studies, including Kahai and Cooper (2003), El-Shinnawy and Markus (1998) and Rice et al (1998) suggest that features of communication systems (such as ease of use, flexibility, and adaptability) can be important additional determinants of use and need to add more predictors of media choice and performance to media richness theory (Kahai and Cooper, 2003).

For today's medical field, information sources not only include traditional media (e.g., print-based such as books, newspapers, and magazines; audiovisual such as radio, TV, and movie; people such as friends, physicians, and patients; and organizations such as NIH and HMO), but also newer media (e.g., electronic such as website, email, and chat board) (Jefford and Tattersall, 2002; Hertzum et al, 2002). For example, the use of non-print methods to convey information has been encouraged numerous researchers trying to inform or educate low-literacy patients (Barbour and Blumenkrantz, 1978; Gagliano, 1988; Doak et al, 1996). Also, many support groups and telephone services enable patients to seek emotional support in addition to specific information (Mossman et al, 1999). In addition, the electronic media bring several new advantages for patients such as convenient access to a massive volume of information and ease of updating information (Murray et al, 2003), although they also have disadvantages, e.g., the quality of information from the existing cancer-related websites is quite variable (Hoffman-Goetz and Clarke, 2000; Silberg et al, 1997). Hence, in addition to the Media Richness Model, there are different strengths and weaknesses for both the traditional and the newer media for the purpose of better understanding medical information sources (See Table 2).

Table 2: Medical Information Sources: Strengths and Weaknesses

Source Type	Examples	Strengths	Weaknesses
Interpersonal	Physician Patient Friend	-Immediate feedback (Wilson, 1997) -Social support (Wilson, 1997) -Emotional support (Mossman et al, 1999)	-Unknown effectiveness (Jefford & Tattersall, 2002) - Limited time (physicians) (Chen and Siu, 2001)
Print-based	Leaflet Book Newspaper Magazine	-Portable (Savolainen, 1995) -High printing quality (Savolainen, 1995; Whelan et al, 1998) -Long tradition of use (Savolainen, 1995)	-Require high-literacy (Cooley et al, 1995)
Audiovisual	Radio, TV, Movie	-Commonness (Barbour & Blumenkrantz, 1978; Gagliano, 1988; Doak et al, 1996) -Low-literacy (Barbour & Blumenkrantz, 1978; Gagliano, 1988; Doak et al, 1996)	-Biased information (Conesa et al, 2004) -Low credibility (Hertzum et al, 2002)
Electronic	Website Email Chat board	-More neutral (Sproull & Kiesler, 1991) -Less sensitive (Sproull & Kiesler, 1991) -Easiness of updating (Savolainen, 1999) -Rapid searchability (Savolainen, 1999) -Savings in time (Savolainen, 1999) -Independence of time (Savolainen, 1999) -Independence of space (Savolainen, 1999; Fox & Fallows, 2003)	-Require computer/Internet Access (Savolainen, 1999) -Unknown credibility (Jefford & Tattersall, 2002; Hoffman-Goetz & Clarke, 2000; Silberg et al, 1997) -Digital division (Murray et al, 2003) -Lack in-person assessment and nonverbal clues (Fox & Fallows, 2003)

Information Source Horizon

Simply, the information source horizon is a construct indicating the selection of information sources within a perceived information environment and positioning them in the horizon according to their potential to meet the information seeker's information needs, and both the selection and positioning of sources are based on the judgments of source accessibility and quality (Savolainen et al, 2004).

According to Savolainen et al (2004), the concept of information horizon which has been introduced to information studies by Sonnenwald (1999), provides a useful starting point for the analysis of source preferences. She proposes that within a context and situation, there is an "information horizon", which may consist of a variety of information resources such as colleagues, librarians, books, documents, information retrieval tools, and web pages (Sonnenwald, 1999).

Based on this view, when such horizons are created in a broader context, an information source horizon arises, which refers to a set of information sources of which the information seeker is aware and of which he or she may have obtained use experiences (Savolainen et al, 2004). The selected information sources are positioned in a preference order within the horizon so that the most important ones will be placed closest to the information seeker and the least relevant farther on (See Figure 2).

With this source horizon, Savolainen et al (2004) investigated how people would draw the information source horizon as a subjective map of source preferences for self-development purposes. The result noted that in the participants' information source horizons, human sources such as friends and colleagues were preferred, followed by print media such as newspapers and books, and networked sources were ranked third among six source types (See Table 3).

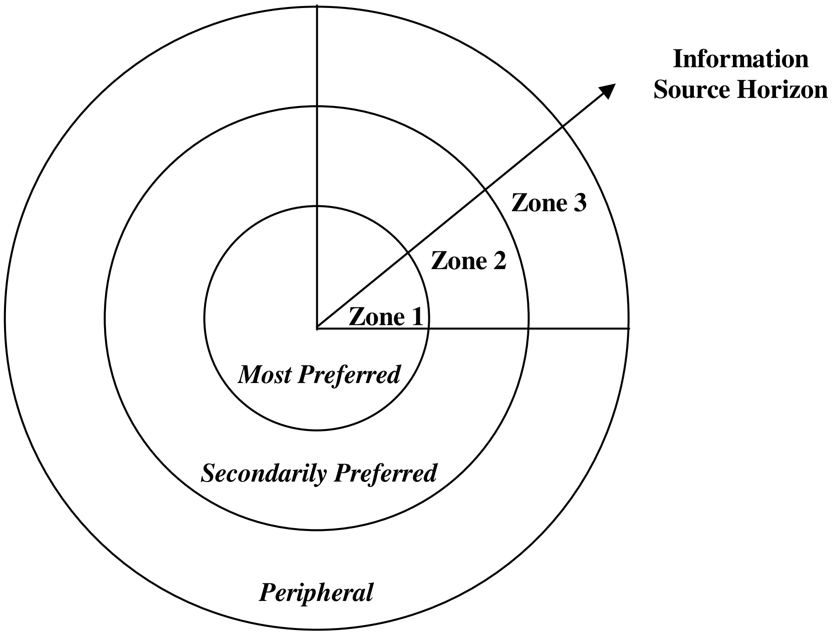


Figure 2: Information Source Horizon and Zones of Source Preferences source: Savolainen et al (2004)

Legend: Zone 1 = most strongly preferred information sources;
Zone 2 = secondarily preferred information sources;
Zone 3 = peripheral information sources.

The study also notes that, in Zone 1, the repertoire of information sources is considerable. Compared to Zone 1, the sources showed more variety in Zone 2, the number of mentioned sources and channels was higher, and the strong variation is exemplified by the fact that only a few sources were mentioned more than once. In Zone 3, the distribution of sources was even broader than within Zone 2: fewer sources were mentioned more than once, and incidentally, all source types were mentioned almost equally. Interestingly, the number of sources placed in Zone 3 is not substantially lower than in Zone 1. Details about information sources in the three zones are as follows (See Table 3).

Table 3: Information Source Comparison

source: Savolainen et al (2004), Daft et al (1987), Ambra and Rice (1994)

Source Type	%/100 mentioned by informants				Media Richness
	Zone 1	Zone 2	Zone 3	Total	
Human sources	31.4	28.2	16.6	76.2	High
Networked sources	28.6	13.0	13.3	54.9	Low - Medium
Printed media	25.7	23.9	16.6	66.2	Low - Medium
Organizational sources	8.6	6.5	16.6	31.7	High
Broadcast media	0.0	17.4	16.6	34.0	Medium - High
Other sources	5.7	10.9	20.0	36.6	
Total	100.0	100.0	100.0		

However, the Information Source Horizon have been only tested for everyday life information seeking (Savolainen et al, 2004) but not yet in the medical field, where the medical information seekers (e.g., patients and their companions) might also have information horizons: some patients cope with their disease by searching for a lot of information from different sources, both sources inside and outside the health care system; some patients seek information from other sources than the hospital staff only to a limited degree (Carlsson and Strang, 1999; Manfredi et al, 1993); and other patients obtaining cancer-related information from magazines rather than the health care provider or a more authoritative source (Johnson and Meischke, 1993; Meischke and Johnson, 1995).

For a specific example, the physician may be a perfect consultant for the patient to make an informed decision (Forsythe et al, 1992), but they are often not able to satisfy the demand that cancer patients and their families desire information as much as possible because of limited time in busy clinical practices and a lack of training in communication skills (Meredith et al, 1996; Fallowfield et al, 1994; Cassileth et al, 1980; Chen and Siu, 2001). As a result, patients and their families often seek other sources for POMI (Chen and Siu, 2001), and consult more than one source of information because of dissatisfaction with the information they receive from a simple source (Stein, 1981). That is, situational factors affect the choice of information source and many situations are resolved through the use of a combination of several types of sources (Hertzum et al, 2002).

However, no study has surveyed the information source horizon of cancer patients and compared it with the general horizon structure. It is unknown, if cancer patients follow the same construct of the information source horizon as the general population. This is the basis of the following hypotheses:

H3P: Cancer patients follow the same construct of information source horizon as the general population.

- **H3Pa:** Cancer patients follow the same construct of information source horizon as the general population in the past.
- **H3Pb:** Cancer patients follow the same construct of information source horizon as the general population in the future.

H3C: Companions follow the same construct of information source horizon as cancer patients.

- **H3Ca:** Companions follow the same construct of information source horizon as cancer patients in the past.
- **H3Cb:** Companions follow the same construct of information source horizon as cancer patients in the future.

Demographics and Medical Information Source Preferences

As it was stated before, the ability to clearly determine patients' and their companions' previous and potential medical information sources can help both physicians and patients make more efficient communication and effective decisions (Dranove, 1988; Labelle et al 1994; Kleffens et al 2003; Basch et al, 2004). Several studies have attempted to identify predictors of informational need (Blanchard et al, 1988; Derdiarian, 1987). Possible factors include the age, sex, educational attainment of the patient, type of cancer, stage of disease, type of treatment, and time since diagnosis (Jefford and Tattersall, 2002).

Demographic variables, such as age, sex, education, economic status, family situation, and ethnicity, play an important role in patient's information seeking behavior (Jung et al, 2003). These variables may prevent the initial emergence of a patient's coping strategy or may intervene between the acquisition of information and its use (Wilson, 1997). For example, Moorman and Matulich (1993) found that high knowledge levels did indeed facilitate information acquisition but also that, when health motivation is high, those with higher health knowledge will perform more actions relating to their health than individuals with lower knowledge levels.

In addition, demographics is a major resource of the various access influences, constraints, and judgment/assessment factors during the process of seeking information. For example, Fox and Fallows (2003) found that higher Internet usage was associated with more education, greater income, and younger age; and women, better-educated, and more experienced Internet users are more likely to exchange health-related email.

That demographics is an influential factor was confirmed by Mills and Davidson (2002), who also proposed that factors that may influence patients' information seeking preferences include the time from diagnosis, age, gender, education, type of cancer, treatment and stage of disease. For example, the well-known socioeconomic predictors for Internet nonuse, that is, factors contributing to the "digital divide", also cut across the population of persons with cancer: those using the Internet are mostly better educated, and have a higher income than nonusers, and they are more likely white (Eysenbach, 2003).

However, there is considerable disagreement as to the influence of some of demographic variables in information seeking behavior (Mills et at, 2002). Mills and Sullivan (1999) listed several supporting and opposing literature of possible influencing factors on information needs in their paper (See Table 4). Mills and Davidson (2002) suggested in their study that: "Given the conflicting conclusions in the literature it is important to clarify the relationship between Sociodemographic and disease variables and information seeking behavior."

Table 4: Possible Influencing Factors on Information Seeking: the Supporting and Opposing Literature source: Mills and Sullivan (1999)

	Reported as an influencing factor	**Reported NOT to be significant**
Age	Galloway et al (1997) Graydon et al (1997), Derdiarian (1987) Bilodeau & Degner (1996)	Brandt (1991), Luker et al (1996) Hinds and Mood (1995)
Gender	Bliss & Johnson (1995)	Derdiarian (1987)
Education	Bilodeau & Degner (1996) Brandt (1991)	Galloway et al (1997), Graydon et al (1997) Luker et al (1996), Hinds and Mood (1995)
Time since diagnosis	Luker et al (1996), Adams (1991) Northouse (1989)	Bliss & Johnson (1995), Derdiarian (1987)
Type of cancer	Bliss & Johnson (1995)	Derdiarian (1987)
Treatment		Graydon et al (1997), Derdiarian (1987)
Stage	Brandt (1991), Derdiarian (1987)	

Although Rutten et al (2004) drew several broad conclusions about cancer patients' information sources (e.g., older patients demonstrate greater reliance on information provided by the cancer specialist or physician than younger patients; information sources are influenced by economic class; patients with higher educational attainment were also more likely to seek information from a greater range of sources), no conclusion was made whether there are significant differences in information source preferences based on demographic differences. Even the two most recent studies about cancer patients' information source preferences in US (Kakai et al, 2003; Basch et al, 2004) did not either. It is unknown whether demographics can be used as a predictor for patients' preferences of medical information sources. This is the basis for the following hypotheses:

H4P: Demographics can be used as a predictor for patients' preferences of medical information sources.

- **H4Pa:** There is a significant relation between patients' demographics and their preferences of medical information sources in the past.
- **H4Pb:** There is a significant relation between patients' demographics and their preferences of medical information sources in the future.

H4C: Demographics can be used as a predictor for patients' preferences of medical information sources.

- **H4Ca:** There is a significant relation between patients' demographics and their preference of medical information sources in the past.
- **H4Cb:** There is a significant relation between patients' demographics and their preference of medical information sources in the future.

Medical Information Quality

As previously mentioned, although most of the cancer-related information is provided by staff in health care, if patients do not get sufficient information there is a risk that they might rely primarily on POMI or nonmedical sources to satisfy their need (Carlsson, 2000). However, the quality of medical information from different media, origins and sources are not evenly distributed (Solano et al, 2003). Even though we know well about the strengths and weaknesses of various information sources (See "Medical Information Source Horizon" section), "quality, like beauty, is in the eye of the beholder; and it is users' views we should be seeking" (Purcell et al, 2002). Therefore, it is important to know how cancer patients and their companions think about the medical information quality from various information sources. Moreover, the continued evaluation of the sources from which cancer patients seek information is necessary to track potential shifts in sources of information access (Rutten et al, 2004), because it is noticed that the judgments drawn from the prior experiences of using various information sources have an impact on the future use of information sources (Hertzum et al, 2002),

Some studies have concerned cancer patients' judgments of the information quality of different sources (Mills and Davidson, 2002; Basch et al, 2004). However, Mills and Davidson's study does not include companions' judgments, Basch et al's study is limited within the comparison between electronic and nonelectronic sources, and neither study has addressed the impact of previously perceived information quality on cancer patients' future information source preferences. It is unknown, if cancer patients will continue to use the same medical information sources because they believe the information qualities of those sources are above the average, and will not continue to use the medical information sources whose information quality they think is below the average. This is the basis for the following hypotheses:

H5P: Cancer patients will continue to use the same sources for more medical information in the future is in direct proportion to their judgments of the information quality of those sources.

H5C: Companions will continue to use the same sources for more medical information in the future is in direct proportion to their judgments of the information quality of those sources.

Conclusions from the Literature Review

There is no doubt that today's patients and their companions use various sources of health information to gain knowledge about their illness. As affirmed in this chapter, understanding *who* searches for information, *why* they search for information (*importance*), *what* they need to know (*topic*), *when* during the course of care (*stage*), and *where* they receive information (*source*) becomes vital to ensuring the delivery of quality care and to making informed decisions. Therefore, it is important to clarify the relationship between socio-demographic (*predictor*) and medical information searching, that is, to discover "who" is searching and how they structure their source horizon. It is also important to highlight the *information quality* patients and companions get from these sources, since judgments drawn from the previous experiences have an impact on the future use of information sources.

A review of the literature indicates that very limited research has been done to study cancer patients' and their companions' medical information sources, especially the comparison between patients and companions, their opinions about information benefits, their evaluation of information quality from various sources, and whether demographics can be used as a predictor for their future source preferences. Moreover, none of the articles about patient information sources have included media richness model and information source horizon theory, which could give health care providers a better understanding about the basic frame of patients' information source choices. The media richness model, which has been used in numerous media studies, and the information source horizon model, which has been often used in the general information seeking field, has not been used to evaluate Patient Obtained Medical Information (POMI) or Companion Obtained Medical Information (COMI) in the cancer field. More research is needed to determine where patients and companions really go or will go for what type of information, and how they really evaluate the quality of the information from which they may get benefits to better cope with cancer.

CHAPTER III

RESEARCH MODEL AND DEVELOPMENT OF INSTRUMENTS

Research Model

Based on the previous literature review, a research model named "Cancer Patients and Companions Medical Information Sources (CPC-MIS)" was developed (See Figure 3). There are two parts in this model: 1) Cancer Patients' Medical Information Sources (See details in Figure 4); and 2) Companions' Medical Information Sources (See details in Figure 5). These two parts have an effect on each other, and jointly influence the medical decision for the cancer patient.

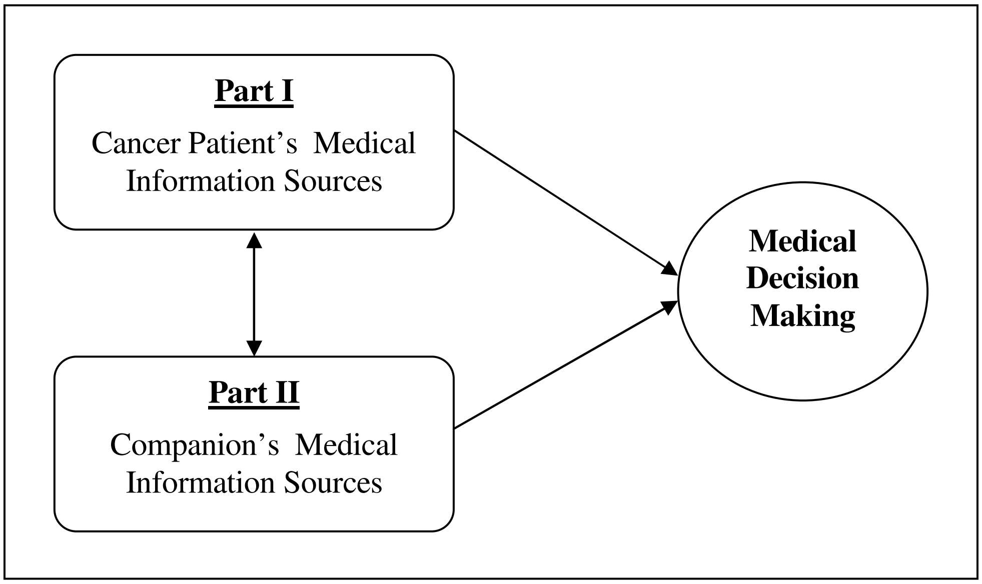


Figure 3: Research Model
Cancer Patient's and Companion's Medical Information Sources (CPC-MIS)

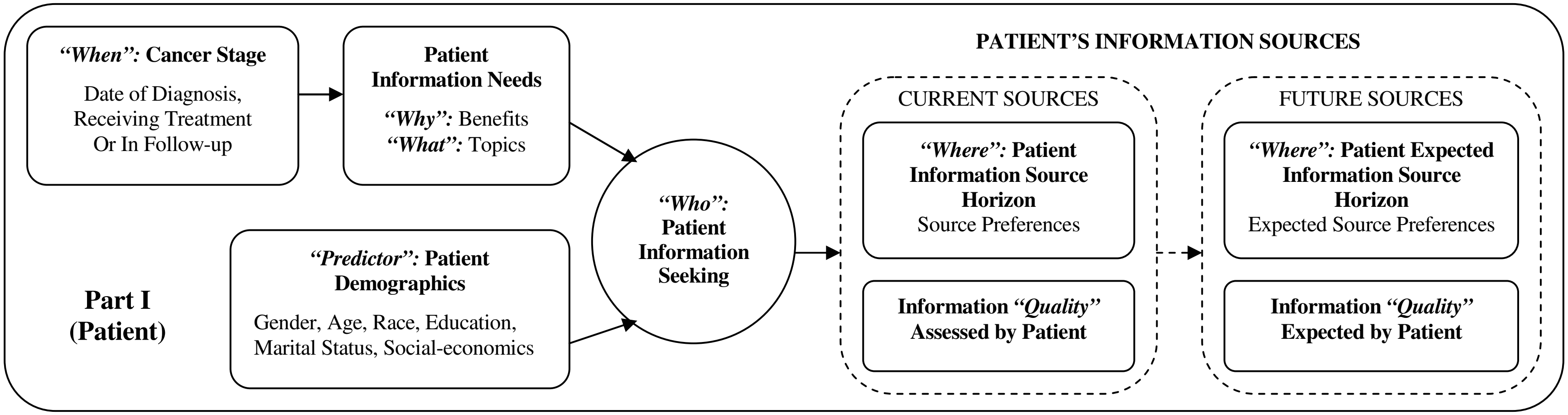


Figure 4: Research Model Part I (Patient Obtained Medical Information Sources)

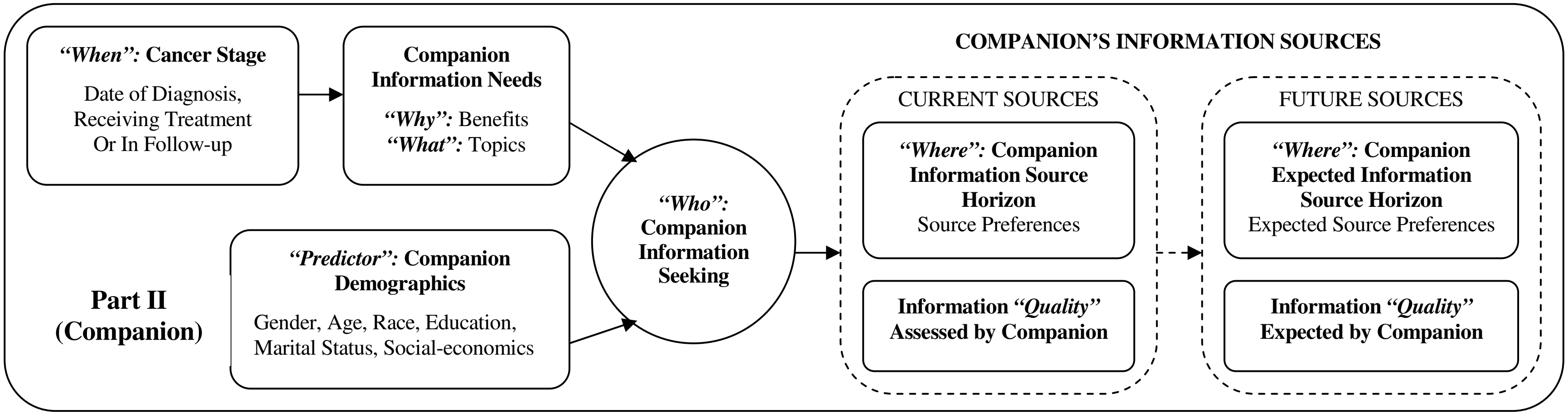


Figure 5: Research Model Part II (Companion Obtained Medical Information Sources)

In the first part, Patient Obtained Medical Information (POMI) Sources, there are five sections (See Figure 4): 1) Patient Information Seeking (*who*), which sits in the center of the model; 2) Patient Information Needs, which includes information benefits (*why*, e.g., more involvement in decision making) and information topics (*what*, e.g., information of diagnosis and treatment); 3) Cancer Stage (*when*, e.g., date of diagnosis, receiving treatment or in follow-up); 4) Patient's Information Sources (*where*), which includes Current Sources and Future Sources, both consisting of Patient Information Source Horizon (e.g., preferences for physicians, pamphlets, and mass media) and Information Quality Assessed by Patients (*quality*, e.g., poor, average, or excellent); 5) Patient's Demographics (*predictor*, e.g., age, income, race, and type of cancer).

Stage has an effect on *Information Need*: which stage the cancer patient is in influences what information topics he or she want to know and what benefits he or she believe one can receive from the information. In the same way, *Demographics* has an effect on *Information Need* too. Furthermore, *Information Need* and *Demographics* simultaneously affect patient's information seeking behavior: both contribute to shaping the patients' information seeking behaviors, which have led them to various information sources. Therefore, both *Information Need* and the *Demographics* indirectly influence *Current Sources*. Finally, *Current Sources* have an influence on the *Future Sources*: where the cancer patient might go in the future for medical information is based on his or her past experiences of information seeking and the information quality he or she believes for various information sources after these experiences.

Similarly, in the second part, Companion Obtained Medical Information (COMI) Sources, there are also five sections (See Figure 5): 1) Companion Information Seeking (*who*), which sits in the middle of the model; 2) Companion Information Needs, which includes information benefits (*why*, e.g., more involvement in decision making) and information topics (*what*, e.g., information of diagnosis and treatment); 3) Cancer Stage (*when*, e.g., date of diagnosis, receiving treatment or in follow-up); 4) Companion's Information Sources (*where*), which includes Current Sources and Future Sources, both consisting of Companion Information Source Horizon (e.g., preferences for physicians, pamphlets, and mass media) and Information Quality Assessed by Companions (*quality*, e.g., poor, average, or excellent); 5) Companion's Demographics (*predictor*, e.g., age, income, race, and type of cancer). This is a parallel model to the Patient Model. For the two models, we will first test them respectively, and then make a comparison to see if there is any difference between POMI Sources and COMI Sources.

In addition, the purpose of demographics is not only to collect basic information about the patient and the companion - it is more for the purpose to collect potential predictors that might help determine patient obtained medical information (POMI) level or companion obtained medical information (COMI) level (e.g., sources and information qualities). Therefore, with corresponding data from *Demographics* and *Current Sources* section, we can get a distribution of patient/companion demographics and POMI/COMI level. Similarly, with corresponding data from *Demographics* and *Future Sources*, we can get a distribution of patient/companion demographics and POMI/COMI level. For future information sources, patients or companions with same demographics may behave similarly when seeking medical information, since they may be influenced by the same information seeking factors; thus, they may go to similar medical information sources and get the same level of medical information. On the contrary, patients or companions with different demographics may behave differently when seeking medical information, since they are probably influenced by the different information seeking factors; thus, they may go to different medical information sources and get different levels of medical information. Studying the above two distributions helps us to determine whether demographics can be used as a good predictor of patient or companion obtained information level.

Hence, with this model, the main intent of the study is to: 1) investigate *who* searches for the information about cancer (patient and companion), and compare their medical information seeking behavior; 2) investigate *why* they searches for such information, that is, what benefits they believe they can get from such information; 3) investigate *what* their information needs are by cancer stage (e.g., whether there is similarity between topics searched in the same stage of cancer or whether there is difference between topics searched in different stages of cancer); 4) investigate *where* they go or will go for these information in the past and in the future; and 5) investigate whether demographics can be used as a *predictor* for patient's or companion's medical information source preferences; 6) investigate the information *quality* assessed or expected by cancer patients and their companions for current sources, and the impact of the quality assessment on their future source uses.

Development of Instruments

With these purposes and to test the hypotheses built in Chapter 2, we develop the operational instruments based on the literature review, focus group discussions, and pretests.

Instruments from Literature Review

According to the Research Model, we identify four major areas in instruments: demographics, medical information sources, specific medical topics, and specific websites. For each area, we adopt the appropriate variables from the literature review and build a list of these variables with their corresponding references.

Demographic Variables

For demographic variables, we have included: age, gender, ethnic, education, working status, income, health insurance, marital status, have children or not, computer ownership, Internet access, type of cancer, date of diagnosis, and stages (See Table 5).

Table 5: Citation List of Patient Demographic Information

Demographics	References
Gender	Carlsson (2000), Fox & Fallows (2003), Leydon et al (2000), Mills & Davidson (2002), O'Malley et al (1999), Rimer et al (1993), Wilkinson & Wilson (1983)
Age	Breemhaar et al (1990), Carlsson (2000), Diaz et al (2002), Fox & Fallows (2003), Harris (1998), Leydon et al (2000), Mills & Davidson (2002), O'Malley et al (1999), Pennbridge et al (1999), Satterlund et al (2003), Turk-Charles et al (1997)
Racial Group	Benjamin-Garner et al (2002), Freimuth (1993), Guidry et al (1998), Kakai et al (2003), Michielutte & Diseker (1982), Nicholson et al (2003), O'Malley et al (1999), Rimer et al (1993), Ward et al (1993)
Educational level	Benjamin-Garner et al (2002), Brown et al (1993), Carlsson (2000), Diaz et al (2002), Turk-Charles et al (1997), Jubelirer et al (1994), Kakai et al (2003), Ward et al (1993) O'Malley et al (1999), Satterlund et al (2003), Guidry et al (1998), Freimuth (1993)
Working status	Kreps & Kunimoto (1994), Wilkinson & Wilson (1983)
Household income	Benjamin-Garner et al (2002), Diaz et al (2002), Johnson et al (2001), Kreps & Kunimoto (1994), Satterlund et al (2003), Wilkinson & Wilson (1983)
Insurance status	Johnson et al (2001), O'Malley et al (1999)
Marital status	Nicholson et al (2003)
Have children or not	Cohn et al (2003)
Computer ownership	Basch et al (2004)
Internet availability	Basch et al (2004)
Type of cancer	Burrows (1998), Grossarth-Maticek et al (1997), Mills & Davidson (2002), Yeager et al (1997)
Date of diagnosis	Basch et al (2004), Mills and Davidson (2002)
Stages	Fox & Rainee (2000), Johnson (2003), Johnson & Meischke (1993), Satterlund et al (2003)

Medical Information Source Variables

For cancer patients, there is an increasing availability of a wide range of cancer information resources (James et al, 1999). Therefore, there are bundles of medical information sources that cancer patients might be possible to use (See Table 6).

Table 6: Typology of cancer patients' information sources source: Rutten et al (2004)

Category	Top Subcategory
Health professionals	Physician, nurse, other health professionals in general
Printed materials	Books, brochures, magazines and newspapers
Media	TV, radio, or videos, Internet
Interpersonal	Friends, family, support groups or support services, other patients
Organizational and scientific resources	Telephone information services, charitable or professional organizations, medical journals or books, health care organizations

From the literature review we have included the following variables as the instruments of medical information sources: physician/nurse/healthcare provider, other health professional/consultant, educational program by HMO/hospital, support group, other patients, narratives, relatives/friends/Acquaintances, national/local information services, leaflets/pamphlets, medical journals, books, Internet/medical websites, E-mail, telephone/helpline, TV, radio, newspapers, magazines, audio/video tapes, films, chat-room, and message board (See Table 7).

Table 7: Citation List of Patient-Obtained Medical Information Sources

Medical Information Sources	References in the Medical Field
Physician/Nurse /Healthcare Provider	Cohn et al (2003), Diaz et al (2002), James et al (1999), Kakai et al (2003), Leadbeater (2001), Mills and Davidson (2002), Mossman et al (1999), O'Malley (1999), Pautler et al (2001), Pennbridge et al (1999)
Other Health Professional /Consultant	Cohn et al (2003), Horrigan et al (2000), Kakai et al (2003), Kleffens et al (2003), Mills and Davidson (2002), Mossman et al (1999), O'Malley (1999), Pautler et al (2001)
Educational Program by HMO/Hospital	Diaz et al (2002), Pennbridge et al (1999)
Support Group	Cohn et al (2003), Mills and Davidson (2002), Mossman et al (1999)
Other Patients	Carlsson (2000), Johnson et al (2001), Kakai et al (2003), Kleffens et al (2003), Pautler et al (2001)
Narratives	Carlsson (2000), James et al (1999), Kakai et al (2003), Mills and Davidson (2002)
Relatives/Friends /Acquaintances	Carlsson (2000), Cohn et al (2003), Diaz et al (2002), Johnson et al (2001), Kleffens et al (2003), Leadbeater (2001), McCreadie and Rice (1999), Mills and Davidson (2002), O'Malley (1999), Pautler et al (2001), Pennbridge et al (1999)
National/Local Information Services	Leadbeater (2001), Mossman et al (1999)
Leaflets/Pamphlets	Cohn et al (2003), Gwadry-Sridhar et al (2003), James et al (1999), Kakai et al (2003), O'Malley (1999), Pautler et al (2001)
Medical Journals	Diaz et al (2002), O'Malley (1999)
Books	Carlsson (2000), James et al (1999), McCreadie and Rice (1999), O'Malley (1999), Pennbridge et al (1999)
Internet/Medical Websites	Carlsson (2000), Cohn et al (2003), Diaz et al (2002), Fox and Fallows (2003), Horrigan et al (2000), James et al (1999), Kakai et al (2003), McCreadie and Rice (1999), Mills and Davidson (2002), Pautler et al (2001), Pennbridge et al (1999)
E-mail	Fox and Fallows (2003), McCreadie and Rice (1999)
Telephone/Helpline	Carlsson (2000), Horrigan et al (2000), Kakai et al (2003), Pennbridge et al (1999)
TV	Carlsson (2000), Cohn et al (2003), Diaz et al (2002), James et al (1999), Kakai et al (2003), McCreadie and Rice (1999), Mills and Davidson (2002), O'Malley (1999)
Radio	Carlsson (2000), Cohn et al (2003), Diaz et al (2002), James et al (1999), McCreadie and Rice (1999), Mills and Davidson (2002), O'Malley (1999)
Newspapers	Carlsson (2000), Cohn et al (2003), Diaz et al (2002), James et al (1999), O'Malley (1999)
Magazines	Carlsson (2000), Cohn et al (2003), Diaz et al (2002), James et al (1999), McCreadie and Rice (1999), O'Malley (1999)
Audio/Video Tapes	James et al (1999), McCreadie and Rice (1999), Pautler et al (2001)
Films	James et al (1999), McCreadie and Rice (1999)

Medical Information Topics

Basch et al (2004) listed several medical topics in their survey of cancer patients and their companions: diagnosis and treatment, nutrition, complementary medicine, pain management, and clinical trials, etc. They found that most Internet users sought information on diagnosis and treatment, and many inquired about drugs, treatment side effects, physicians, and hospitals. However, the results are almost limited within cancer patients and their companions who own computers (64% and 76%) and have the access to the Internet (58% and 68%).

Similarly, Rutten et al (2004) completed a literature review about cancer patients' information needs including the findings from 91 articles, and developed a more comprehensive list of medical information topics (See Table 8). From this list, we adopted the most popular medical topics, put the similar ones together and categorized them into the following 15 types: diagnosis and treatment, complementary and alternative medicine, clinical trials and genetics services, coping with cancer (side effects and complications), pain management, cancer biology, drugs and side effects, nutrition, patient experiences, cancer prevention/genetics/causes, oncologists, cancer hospitals, support and resources, insurance/financial assistance, and cancer literature. For these 15 topics, we ask the participants which they have searched in the past and which they feel they may search in the future. There are also blanks for respondents to add any specific topics that were not included in the survey.

Specific Medical Websites

Basch et al (2004) investigated a survey to evaluate the use of electronic and nonelectronic informational resources by patients and their companions. In the Internet part, they listed several large general medical sites, such as WebMD, as well as cancer-specific sites, such as those of the

ACS and the NCI. They also provided blank space for Internet users to identify the three websites that they found to be most helpful, including sites not included in the provided list. They noted that government-sponsored websites (e.g., the National Institutes of Health and NCI websites) were more commonly used than were commercial sites.

The present study adopts most of the specific websites listed in Basch et al's (2004) survey (See questionnaire), and add search engines (e.g., Google and Yahoo) as another choice since more and more people are using search engines. There are also blanks for respondents to add any specific websites that were not included in the survey.

Focus Group

In June 2004, a focus group meeting was held in the Vanderbilt Ingram Cancer Center to provide information and advices for the model and the instruments of "Cancer Patients' and Companions' Medical Information Sources". Sixteen health care providers participated, including physicians and nurses, with experience in cancer care. The goal was to identify those items that they considered important to analyze when looking at cancer patients' and their companions' medical information sources.

The author of this study introduced herself to the audience, explained the main purpose of the study, listed literature review of articles addressing demographics and information sources in medical field, presented the research model and instruments, and described the methodology to follow during the survey.

Most of the physicians and nurses contributed their ideas, experiences, and recommendations for this study. For example, they pointed out that "message board" and "chat room" should be added into the potential medical information sources. They also made some suggestions for the questionnaire development and ways to make the survey process more efficient.

Development of Questionnaire

The first version of the questionnaire has two pages divided into two parts: Part A "Background Information" and Part B "Medical Information Sources". Part A has 11 basic socio-demographic questions including stage of cancer, type of cancer, gender, age, racial group, education, working status, household income, marital status, children, and whether the participant is waiting to see the doctor or has seen the doctor. Part B focuses on the medical information sources the participant went in the past, and how good he/she thinks the quality of the information got from those sources is. In this version, there is a simple paragraph stating the objective of this survey at the very beginning of the questionnaire, and there is an example to show the participant how to fill out Part B. (See Appendix A)

The second version of the questionnaire has three pages divided into three parts: Part A "Background Information", Part B "Medical Information Sources", and Part C "Medical Information Searching". There is no change to Part A and Part B from the first version. Part C is newly added, which focuses on the medical information sources the participant will go in the future, and how good he/she expect the quality of the information from those sources will be. Also, there is an example to show the participant how to fill out Part C. (See Appendix B)

The third version of the questionnaire has three pages divided into two parts: Part A "Background Information" and Part B "Medical Information Sources". There is no change to Part A from the second version. Part B in this version actually combines Part B and C of the second version into one page with rearrangement of the order of source choices; and there is a whole page, which includes the guidelines and an example, to show the participant how to fill out Part B. (See Appendix C)

The fourth version of the questionnaire has three pages divided into two parts: Part A "Background Information" and Part B "Medical Information Sources". There is no change to Part A from the third version. The only change to Part B in this version is an additional example showing the participant how to fill out this part. That is, there is one example for the medical information sources in the past and one for the future. (See Appendix D)

The fifth version of the questionnaire has three pages divided into three parts: "Instructions", Part A "Background Information" and Part B "Medical Information Sources". The biggest change of this version is: there are overall instructions followed by revised examples for Part B at the very beginning of the questionnaire. The instructions mainly tell the participant the objective of this survey and general information and guidelines for each part. One question about medical insurance is added to Part A. For Part B, it is divided into two sections: Section B1 and Section B2, which are focused the past sources and future sources respectively. (See Appendix E)

The sixth version of the questionnaire has four pages divided into three parts: "Instructions", Part A "Background Information" and Part B "Medical Information Sources". In this version, the only change is: the examples for Part B are combined into one and moved right at the beginning of this part. (See Appendix F)

The seventh version of the questionnaire has five pages divided into four parts: a "Letter of Confidentiality", "Instructions", Part A "Background Information" and Part B "Medical Information Sources". The letter of confidentiality covers the information about the investigators, survey purposes, expected time to finish answering the questionnaire, participants' rights, approval information and contact information. Participants are also thanked at the end of this letter for their willingness to contribute their share to this research. There are a few minor changes (either legends addition or format adjustment) to both Part A and Part B. (See Appendix G)

The eighth version of the questionnaire has seven pages divided into four parts: the "Letter of Confidentiality", "Instructions", Part A "Background Information" and Part B "Medical Information Sources". Sever changes are made for this version: 1) since it is decided that the study not only ask the cancer patients about their medical information sources but also will compare the source preferences between the patients and their companions, the questionnaire now has to be revised to be appropriate for both the patients and the companions to take; 2) since specific medical topics and websites are added to the interests of this study, the questionnaire now has to add sections about the topics and websites, too; 3) the study will need background information from the patient, such as date of diagnosis, computer ownership, and Internet access availability. Therefore, in this version, the letter of confidentiality adds the companions as readers; a few questions are added to Part A: whether the participant is a patient or the companion, what is the relationship between the patient and the companion, what whether the participant owns any computer or not, whether he/she has Internet access, and what date is the patient's diagnosis day. Part B has been divided into three sections: Section B1 medical information sources (both the past and the future), Section B2 specific medical topics (both the past and the future), and Section B3 specific websites (both the past and the future). There are respective guidelines and examples for all the sections of Part B. There is an addition of "message board" and "chat room" as medical information sources as suggested by the focus group and a minor rearrangement for Section B1. (See Appendix H)

The ninth version of the questionnaire has six pages divided into four parts: the "Letter of Confidentiality", "Instructions", Part A "Background Information" and Part B "Medical Information Sources". There are no big changes in this version but just a few minor word corrections and format improvements. Since it is a little bit wordy in the questionnaire and Section B2 and B3 are quite clear themselves, the detailed guidelines and specific examples for both of these two sections thus have been deleted to make it look more neat. (See Appendix I)

The tenth and final version of the questionnaire has seven pages divided into five parts: the "Letter of Confidentiality", "Instructions", Part A "Background Information", Part B "Medical Information Sources", and Part C "Information Benefits". There is no change for the first four parts. The newly added Part C asks participants about their opinions of information benefits. (See Appendix J)

Pre-Test 1

"Questionnaire Version 6.0" was distributed to 11 people on Vanderbilt University Campus. Respondents included faculty, staff, graduate and undergraduate students. The researcher administered in person each questionnaire and encouraged all the participants to write down any doubts and opinions about the questions, instruments, and formats.

The time for answering this questionnaire was measured. Respondents spent between 5-10 minutes to answer this survey. The average answering time was 7 minutes. Respondents identified a diverse set of problems with this questionnaire.

Respondents reported that the instructions were not clear enough and examples were a little bit wordy. They also pointed that the format needed improvement, too. Changes are made according to this pretest in the questionnaire version 7.0.

Pre-Test 2

“Questionnaire Version 8.0” was distributed to 15 people on Vanderbilt University Campus. Respondents are mainly graduate students. The researcher administered in person each questionnaire and encouraged all the participants to write down any doubts and opinions about the questions, instruments, and formats.

The time for answering this questionnaire was measured. Respondents spent between 5-12 minutes to answer this survey. The average answering time was 9 minutes. Respondents identified just one or two problems with this questionnaire.

Respondents reported that there is one misspelling in one of the choices. They also pointed that it is a little bit wordy and it would be better to make the sample page distinguished from the others, and enlarge the sentence “SKIP if never used the Internet” to a eye-striking font size. Changes are made according to this pretest in the questionnaire version 9.0.

Conclusion of Instrument Development

After all the above instrument development processes including a literature review, the focus group discussions, and two pretests, we have all the demographic variables, medical information source variables, specific topics, and specific websites well organized in a seven-page questionnaire with guidelines and examples, which is used for the pilot survey and the main survey (See Appendix J).

CHAPTER IV

METHODOLOGY

To test the hypotheses developed in Chapter 2, a survey was implemented in the Oncology clinic of the Vanderbilt Ingram Cancer Center (VICC). The subject population is cancer patients and their companions, who are visitors in the VICC clinic. Inclusion criteria included: 1) able to read and write English; 2) 18 years old and above, and 3) enrolled in the outpatient cancer clinic or served as a companion. There is no risk for them to answer the questionnaire. There are no identifiers on the survey. The type of data is mainly qualitative, not linked to specific individuals.

To implement the survey, the IRB approval (IRB# 040120) was received for the seventh version, the first IRB amendment approval and SRC approval (VICC SUPP 0460) were received for the eighth version, and the second IRB amendment approval was received for the tenth version. The full study was done with the tenth and final version.

IRB Approval and Amendment

To conduct this study, which involves human subjects, it was mandatory to have an approval from the Vanderbilt University IRB (Institutional Review Board), where is the institution in charge of reviewing proposed human subject research.

The data of this study are to be collected from patients, and the process mentioned above applies to this study because interaction, defined by the IRB "includes communication or interpersonal contact between investigator and subject" (Policy I.A). And the Vanderbilt IRB also mentions "if there is any possibility that the investigator may want to publish or disseminate the resulting data in the future, the protocol must be submitted for IRB review" (Policy I.A). Therefore, both policy I.A and I.C apply for the present study.

For this study, request of "exemption for survey or interview" was submitted because: 1) "the subjects and responses cannot be identified directly or indirectly"; 2) "the research does not substance and/or child abuse, illegal conduct or sexual behavior"; 3) "the responses, if they became known outside the research, could not conceivably be damaging to the subject's employability or financial standing, or could not place the subject at risk of criminal or civil liability"; and 4) "the study population is sufficiently large that reported responses cannot be related to specific individuals".

The author's responsibilities include: 1) the "Request for Exemption" (IRB Form #1102) is completed in its entirety and submitted to the IRB Front Office for processing, and the original Request for Exemption form plus 2 copies as well as 3 copies of any background information are submitted; the application and instructions to complete the application are located on the IRB website: http://www.mc.vanderbilt.edu/irb/; 2) the investigator replies to all requests for revisions and/or clarifications requested by the pre-reviewers or reviewers, when applicable; 3) any changes to the approved study within the first year are submitted to the IRB using the "Request for Amendment" (IRB Form # 1104), and changes are not implemented prior to IRB review and approval; 4) any proposed changes in the exempt study initiated after the first anniversary of the IRB approval date are submitted in a new "Request for Exemption" application (IRB form # 1102); 5) the Investigator is responsible for assuring that the exempt research is carried out in an ethical manner that includes participant protections (i.e., confidentiality).

Since there were changes and additions to the questionnaire after the IRB approval, it was also mandatory to have an amendment approval from the Vanderbilt University IRB. (See

Appendix L for all the documents submitted to the IRB Committee for exemption and amendment, and see Appendix M for all the approval letters from the IRB Committee.)

SRC Approval

The SRC follows a three-step process: 1) BEFORE EXPERIMENTATION, the SRC reviews and approves experimental procedures for projects involving human subjects, nonhuman vertebrates, pathogenic agents, controlled substances, recombinant DNA, and human/animal tissue to make sure they comply with the Rules and any pertinent laws. Human studies reviewed and approved by a properly constituted IRB do not have to be reviewed by the SRC until regional competition; 2) AFTER EXPERIMENTATION AND SHORTLY BEFORE THE REGIONAL FAIR, the SRC reviews and approves those same projects to make sure that students followed the approved research plan and the Rules; 3) AFTER EXPERIMENTATION AND SHORTLY BEFORE THE REGIONAL FAIR, the SRC also reviews all remaining projects to make sure students followed the Rules. (See Appendix N for the proposal submitted to the SRC Committee, and see Appendix O for the approval letter from the SRC Committee.)

Clinical Setting

Anchored by the Frances Williams Preston building, Vanderbilt Ingram Cancer Center (VICC) includes the Henry-Joyce Cancer Clinic, inpatient units in Vanderbilt Hospital and Children's Hospital, and more than 100 laboratories throughout Vanderbilt University and medical center (VICC Facts at A Glance, 2003). The VICC is one of only 38 National Cancer Institute-designated Comprehensive Cancer Centers in the United States and the only one in Tennessee to earn this highest distinction from the NCI (VICC Facts at A Glance, 2003). It is ranked among the

Top 10 hospitals for cancer care by U.S. News World Report, and it is the first center to have faculty simultaneously leading three major national cancer organizations – the American Society for Clinical Oncology, the American Association for Cancer Research and the Association of American Cancer Institutes (VICC Facts at A Glance, 2003). The VICC has an increasing clinical volume (an average of 7.25 percent each year since 1997) reaching more than 40,000 outpatient visits per year. It has enrolled more than 7,500 patients into clinical trials since 1998, and offers more than 150 clinical trials at any one time for adult and pediatric patients (VICC Facts at A Glance, 2003). Both the pilot test and full test of this study were implemented in the Henry-Joyce Cancer Clinic at Vanderbilt (Please see attached approval letter from Medical Director of the Patient Care Center for Cancer and Oncology clinic).

Pilot Study

With all the approvals and after a meeting with Dr. Barbara Murphy, Director of the Pain and Symptomatic Cancer Group at Vanderbilt Ingram Cancer Center, a pilot test of "Questionnaire Version 9.0" was implemented. Cancer patients and their companions were recruited from the Cancer Clinic at Vanderbilt Ingram Cancer Center, from a weekly outpatient clinic. A total of 28 cancer patients and 14 companions were interviewed from September 16, 2004 to September 17, 2004.

Dr. Murphy introduced the researcher and researcher's assistant to physicians, nurses, and intakes who work in the Cancer Clinic before starting the pilot test. Intakes are responsible for bringing the patient from the waiting room to the patient's room, and checking their vital signs. Oncologists participated in patient's recruitment. A name list of the physician and his/her patients, with the time for each appointment, is attached to the wall. When patients arrive to the clinic, the intake highlights the name of the patient in the appointment list and writes the number of the room where the patients is brought. After being checked by the physician, the patient is marked out from the list.

The researcher and researcher's assistant checked the patient appointment list for each physician, and after having health care provider's authorization, proceeded with the interviews. Nurses, and especially Intakes, were very helpful in this process. They informed the researcher and researcher's assistant if a patient met the requirements for this study.

During the survey, the researcher and researcher's assistant introduced themselves to participants, presented the information letter, and described the study. Patients were asked if they were interested in participating. If the patient agreed to participate, he/she was asked complete the questionnaire. Investigators were ready to offer to read or explain the questionnaire to patients if they required. Patients were informed that the information would be kept confidential. After the questionnaire was completed, investigators confirmed that the information collected had no identifying information. Patients were then thanked for their participating in this study.

The time for answering this questionnaire was measured. Respondents spent between 9-17 minutes to answer this survey. The average answering time was 12 minutes. The feedback from the respondents showed that they thought the questionnaire was clearly stated and comprehensible.

Full Study

Subjects for the full study were recruited over September and October of 2004. Patients and companions were interviewed with following the same approach of the pilot test. The researcher or research assistant contacted each subject in the waiting room to administer the survey. All the participants were told the purpose of the study and mentioned the information contained on the confidentiality letter. At the conclusion of the survey, they were asked if they had any questions or suggestion.

A total of 257 patients and 167 companions were interviewed from weekly outpatient clinic in the Cancer Clinic of Vanderbilt Ingram Cancer Center. The participants represented 29 different kinds of cancer, and were divided up into 8 different categories of cancer: Breast Cancer, Gastro Intestinal Cancer (G.I.), Gynaecological, Head/Neck Cancer, Lung Cancer, Haematological Malignancies and Related Disorders (H.M.), Urinary and Genitourinary Cancers (U.G.), and Other cancers such as melanoma and brain cancer. No problems were identified at this stage regarding the questionnaire and the time to answer it. Statistics and results of this full study are described in more details in Chapter 5.

CHAPTER V

RESULTS AND ANALYSES

This chapter contains two parts. The first deals with a brief description of the sample demographics. The second part, hypothesis testing, describes the results of each hypothesis tested.

All data were coded and entered into a database using SPSS (SPSS for Windows Release 11.01.1; SPSS Inc.). Missing responses, and responses that did not fit into one of the specific item responses were all considered missing. Prior to start any analysis, data were checked with SPSS to confirm that there were no data entry errors.

Sample Demographics

Of the 468 individuals approached, 424 (91%; 257 cancer patients and 167 companions) completed and returned the survey questionnaires. From these 424 questionnaires, 166 patient questionnaires were paired with companion questionnaires. Demographics for responding subjects are listed in Table 8.

Table 8: Demographics of Medical Information Source Survey Responders

Demographic Question		Overall		Patient		Companion	
Characteristic	Response Category	N	%	N	%	N	%
Type of cancer*		424		257		167	
	Breast	57	13.4%	33	12.8%	24	14.4%
	Gastro Intestinal	52	12.3%	31	12.1%	21	12.6%
	Gynecological	50	11.8%	30	11.7%	20	12.0%
	Head & Neck	48	11.3%	32	12.5%	16	9.6%
	Hematological Malignancies	46	10.8%	30	11.7%	16	9.6%
	Lung	56	13.2%	35	13.6%	21	12.6%
	Urinary/Genitourinary	60	14.2%	35	13.6%	25	15.0%
	Other	55	13.0%	31	12.1%	24	14.4%
Date of diagnosis*		424		257		167	
	<= 1 year	248	58.5%	149	58.0%	99	59.3%
	> 1 year	176	41.5%	108	42.0%	68	40.7%
Stage*		386		235		151	
	Receiving treatment	311	80.6%	185	78.7%	126	83.4%
	In follow-up	75	19.4%	50	21.3%	25	16.6%
Relationship to patient		-		-		165	
	Spouse	-	-	-	-	99	60.0%
	Child	-	-	-	-	25	15.2%
	Parent	-	-	-	-	11	6.7%
	Other relatives	-	-	-	-	17	10.3%
	Partner or Friend	-	-	-	-	13	7.9%
Whether live with patient		-		-		162	
	Live in the same household	-	-	-	-	120	74.1%
	Not live in the same household	-	-	-	-	42	25.9%
Gender		424		257		167	
	Male	201	47.4%	140	54.5%	61	36.5%
	Female	223	52.6%	117	45.5%	106	63.5%
Age		419		253		166	
	< 50	149	35.6%	82	32.4%	67	40.4%
	50-65	192	45.8%	115	45.5%	77	46.4%
	> 65	78	18.6%	56	22.1%	22	13.3%
Race		422		256		166	
	White (Non Hispanic)	375	88.9%	223	87.1%	152	91.6%
	African American	36	8.5%	24	9.4%	12	7.2%
	Asian or Pacific Islander	7	1.7%	5	2.0%	2	1.2%
	Hispanic or Latin origin	3	0.7%	3	1.2%	0	0.0%
	Other	1	0.2%	1	0.4%	0	0.0%
Education		418		253		165	
	Elementary	15	3.6%	11	4.3%	4	2.4%
	Some high school (no diploma)	35	8.4%	29	11.5%	6	3.6%
	High school (with diploma)	129	30.9%	79	31.2%	50	30.3%
	Some college	110	26.3%	61	24.1%	49	29.7%
	Bachelor's degree	66	15.8%	36	14.2%	30	18.2%
	Graduate or professional	63	15.1%	37	14.6%	26	15.8%
Working Status		379		227		152	
	Working	155	40.9%	64	28.2%	91	59.9%
	Full-time sick leave	45	11.9%	44	19.4%	1	0.7%
	Retired	125	33.0%	81	35.7%	44	28.9%
	Unemployed	54	14.2%	38	16.7%	16	10.5%
Household Income		373		225		148	
	< $25,000	95	25.5%	59	26.2%	36	24.3%
	$25,000-49,999	108	29.0%	72	32.0%	36	24.3%
	$50,000-74,999	67	18.0%	41	18.2%	26	17.6%
	>= $75,000	103	27.6%	53	23.6%	50	33.8%
Medical Insurance Status		408		247		161	
	Have insurance	395	96.8%	243	98.4%	152	94.4%
	Not have insurance	13	3.2%	4	1.6%	9	5.6%
Marital Status		417		252		165	
	Married, regular partnership	324	77.7%	187	74.2%	137	83.0%
	Single, divorced, widowed	93	22.3%	65	25.8%	28	17.0%
Have children or not		421		255		166	
	Have children	355	84.3%	218	85.5%	137	82.5%
	Not have children	66	15.7%	37	14.5%	29	17.5%
Computer Ownership		421		254		167	
	Own a computer	325	77.2%	186	73.2%	139	83.2%
	Not own a computer	96	22.8%	68	26.8%	28	16.8%
Internet Access Availability		420		254		166	
	Have Internet access	320	76.2%	180	70.9%	140	84.3%
	Not have Internet access	100	23.8%	74	29.1%	26	15.7%

* For companion, it indicates the characteristic of his/her paired patient.

The 257 cancer patients represented 29 different kinds of cancer, and were divided up into eight different categories of cancer: Breast Cancer, Gastro Intestinal Cancer (G.I.), Gynecological, Head/Neck Cancer, Lung Cancer, Hematological Malignancies and Related Disorders (H.M.), Urinary and Genitourinary Cancers (U.G.), and Other Cancers such as melanoma and brain cancer. For date of diagnosis, age, education, and household income, we categorized them into two to six groups based on the original quantitative data for analysis purposes. They were treated as ordinal data when in categories (e.g., age group, date of diagnosis group), and as interval data when in raw numbers (e.g., age in years, date of diagnosis in months). To distinguish, we added the word "group" after the variable name when it was treated as ordinal. For example, "age (group)" is ordinal but "age" is interval.

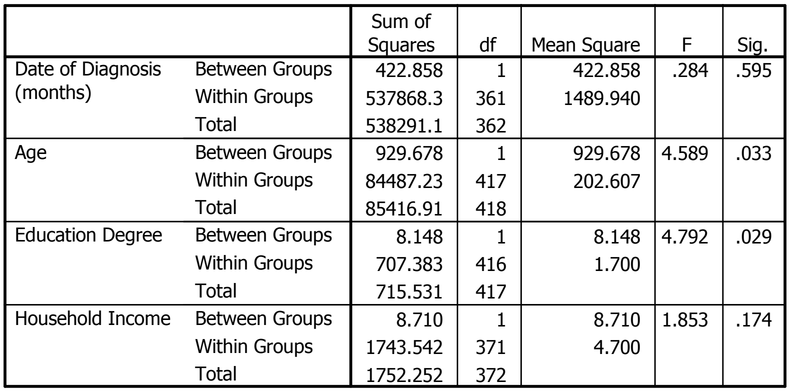
From Table 8, we can see that the responders are well balanced for type of cancer (ranged from 10.8% to 14.2%), date of diagnosis (<= 1 year, 58.5%; >1 year, 41.5%), and gender (male, 47.4%; female, 52.6%). Other than those, more responders seem to be currently receiving treatments (80.6%), between 50 and 65 (45.5%), white (87.1), either working (40.9%) or retired (33.0%), married or in regular partnership (77.7%), mostly having insurance (96.8%), with education degrees higher than some high school (88%) and household income higher than $25,000 (74.5%), and own computers (77.2%) and Internet accesses (76.2%). Companions are mostly spouses (60.0%) and children (15.2%) of the patients, and most of the cases they live in the same household (74.1%).

To compare the demographic characteristics between patients and companions, Chi-square tests were run for nominal variables (such as gender) and ordinal variables (such as age group), and One-way ANOVA tests were run for interval variables (such as age in years) ($\alpha = .05$). Chi-square tests (See Table 9) show that there is no significant difference between patients and companions for date of diagnosis (group), stage of treatment, race, education (group), household income (group), and have children or not; while there are differences for gender (*P* = .000), age (group) (*P* = .049), working status (*P* = .000), medical insurance (*P* = .040), marital status (*P* = .041), computer ownership (*P* = .018), and Internet access availability (*P* = .002). One-way ANOVA tests (See Table 10) show that there is no significant difference for date of diagnosis nor household income, but there are differences for age (*P* = .033) and education degree (*P* = .029).

Table 9: Demographic Differences (Patient vs. Companion)

Demographics	Differences between Patient and Comapnion (N=424)	
	Asymp. Sig. (2-sided)	Approx. Sig.
Date of diagnosis (group)	.435	.790
Stage of treatment	.156	.253
Gender	***.000***	***.000***
Age (group)	***.049***	***.049***
Race	.448	.448
Education (group)	.059	.059
Working status	***.000***	***.000***
Household income (group)	.148	.148
Medical insurance	***.040***	***.026***
Marrital status	***.041***	***.034***
Have children or not	.414	.414
Computer ownership	***.018***	***.017***
Internet access availability	***.002***	***.002***

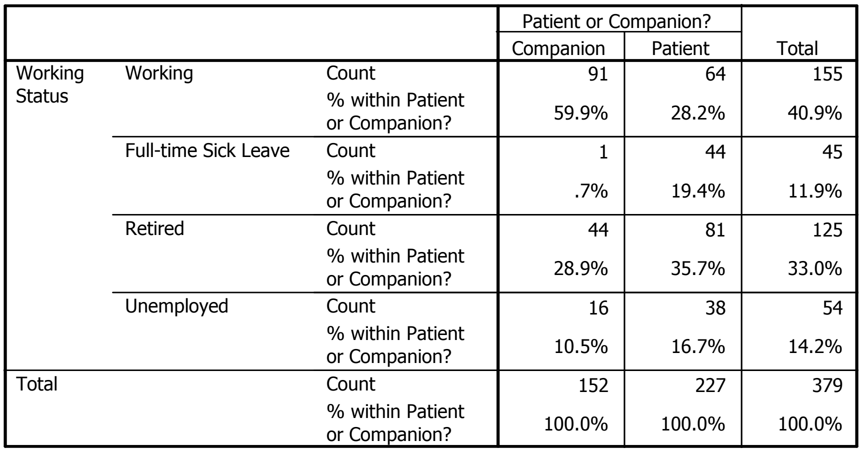
Table 10: ANOVA (Factor: Patient or Companion)



		Sum of Squares	df	Mean Square	F	Sig.
Date of Diagnosis (months)	Between Groups	422.858	1	422.858	.284	.595
	Within Groups	537868.3	361	1489.940		
	Total	538291.1	362			
Age	Between Groups	929.678	1	929.678	4.589	.033
	Within Groups	84487.23	417	202.607		
	Total	85416.91	418			
Education Degree	Between Groups	8.148	1	8.148	4.792	.029
	Within Groups	707.383	416	1.700		
	Total	715.531	417			
Household Income	Between Groups	8.710	1	8.710	1.853	.174
	Within Groups	1743.542	371	4.700		
	Total	1752.252	372			

In order to look into these differences shown above, Frequency Crosstab was run for categorical variables (e.g., working status), and Means Plot was run for dichotomous variables (e.g., gender) and ordinal variables (e.g., age group). Crosstab (See Table 11) shows that the majority of patients are retired (35.7%) at present, but the majority of companions (59.9%) are still working (*P* = .000). Means Plots (See Figure 6) show that: 1) there are 17% more males than females in patient group, but 17% more females than males in companion group (*P* = .000); 2) companions seem to be younger than patients - 8.9% more companions are below 65 and 8.8% more patients are above 65 (*P* = .049); 3) almost all the patients have medical insurance (98%), but not all the companions (94%) (*P* = .040); 4) although both patients and companions are largely in regular partnership, 9% more patients are single (*P* = .041); 5) although both patients and companions own computers for the most part, 10% more patients do not (*P* = .018); 6) similarly, although both patients and companions have Internet access for the most part, 13% more patients do not (*P* = .002); 7) and finally, 10.7% more patients have a education degree lower than the college, but 10.4% more companions have a education degree higher than the college (*P* = .029).

Table 11: Frequency Crosstab for Working Status (Patient vs. Companion)



			Patient or Companion?		Total
			Companion	Patient	
Working Status	Working	Count	91	64	155
		% within Patient or Companion?	59.9%	28.2%	40.9%
	Full-time Sick Leave	Count	1	44	45
		% within Patient or Companion?	.7%	19.4%	11.9%
	Retired	Count	44	81	125
		% within Patient or Companion?	28.9%	35.7%	33.0%
	Unemployed	Count	16	38	54
		% within Patient or Companion?	10.5%	16.7%	14.2%
Total		Count	152	227	379
		% within Patient or Companion?	100.0%	100.0%	100.0%

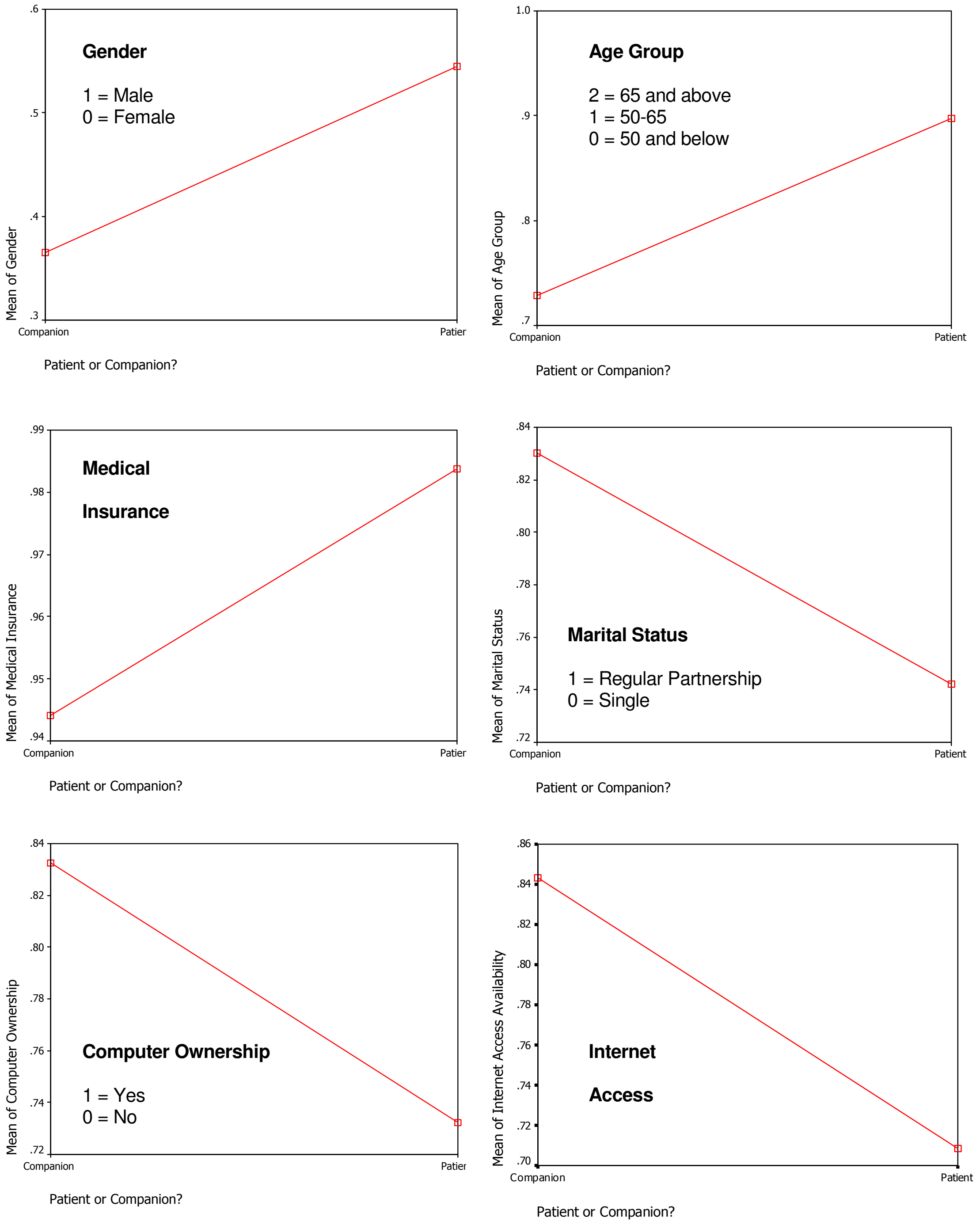


Figure 6: Means Plots (Factor: Patient or Companion)

To compare the demographic characteristics among cancer groups, Chi-square tests were run for nominal variables (such as gender) and ordinal variables (such as age group), and One-way ANOVA tests were run for interval variables (such as age in years).

The Chi-square tests (See Table 12) show that: 1) on the whole, there is no significant difference among cancer groups for stage of treatment, race, education (group), medical insurance, marital status, and computer ownership, while there are differences date of diagnosis (group) (*P* = .000), gender (*P* = .001), age (group) (*P* = .011), working status (*P* = .020), household income (group) (*P* = .000), having children or not (*P* = .019), and Internet access availability (*P* = .017); 2) for patients, only date of diagnosis (group) (*P* = .005) and gender (*P* = .000) are significantly different among cancer groups; 3) and for companions, date of diagnosis (group) (*P* = .017), gender (*P* = .000) and working status (*P* = .002) are different among cancer groups. The One-way ANOVA tests (See Table 13) show that: 1) on the whole, there is no significant difference among cancer groups for household income, but there are differences for date of diagnosis (*P* = .000) for age (*P* = .042) and education degree (*P* = .001); 2) for patients, only education degree is significantly different among cancer groups (*P* = .004); and 3) for companions, only date of diagnosis is significantly different among cancer groups (*P* = .016).

Table 12: Demographic Differences among Cancer Groups

Demographics	Differences among Cancer Groups					
	Overall (N=424)		Patient (N=257)		Companion (N=167)	
	Asymp. Sig. (2-sided)	Approx. Sig.	Asymp. Sig. (2-sided)	Approx. Sig.	Asymp. Sig. (2-sided)	Approx. Sig.
Date of diagnosis (group)	***.000***	***.000***	***.005***	***.005***	***.017***	***.017***
Stage of treatment	.190	.190	.331	.331	.899	.899
Gender	***.001***	***.001***	***.000***	***.000***	***.000***	***.000***
Age (group)	***.011***	***.011***	.054	.054	.235	.235
Race	.071	.071	.415	.415	.199	.199
Education (group)	.130	.130	.166	.166	.463	.463
Working status	***.020***	***.020***	.081	.081	***.002***	***.002***
Household income (group)	***.000***	***.000***	.152	.152	.130	.130
Medical insurance	.280	.280	.731	.731	.283	.283
Marital status	.268	.268	.329	.329	.695	.695
Have children or not	***.019***	***.019***	.062	.062	.333	.333
Computer ownership	.064	.064	.256	.256	.133	.133
Internet access availability	***.017***	***.017***	.121	.121	.087	.087

Table 13: ANOVA by Cancer Groups (Overall)

		Sum of Squares	df	Mean Square	F	Sig.
Date of Diagnosis (months)	Between Groups	42919.06	7	6131.295	4.394	.000
	Within Groups	495372.1	355	1395.414		
	Total	538291.1	362			
Age	Between Groups	2950.330	7	421.476	2.101	.042
	Within Groups	82466.58	411	200.649		
	Total	85416.91	418			
Education Degree	Between Groups	40.236	7	5.748	3.490	.001
	Within Groups	675.295	410	1.647		
	Total	715.531	417			
Household Income	Between Groups	49.913	7	7.130	1.529	.156
	Within Groups	1702.339	365	4.664		
	Total	1752.252	372			

Table 14: ANOVA by Cancer Groups (Patient)

		Sum of Squares	df	Mean Square	F	Sig.
Date of Diagnosis (months)	Between Groups	20492.34	7	2927.477	2.050	.050
	Within Groups	298486.5	209	1428.165		
	Total	318978.9	216			
Age	Between Groups	1608.546	7	229.792	1.100	.364
	Within Groups	51173.81	245	208.873		
	Total	52782.36	252			
Education Degree	Between Groups	37.299	7	5.328	3.061	.004
	Within Groups	426.472	245	1.741		
	Total	463.771	252			
Household Income	Between Groups	28.601	7	4.086	.888	.517
	Within Groups	998.759	217	4.603		
	Total	1027.360	224			

Table 15: ANOVA by Cancer Groups (Companion)

		Sum of Squares	df	Mean Square	F	Sig.
Date of Diagnosis (months)	Between Groups	25156.07	7	3593.724	2.560	.016
	Within Groups	193733.3	138	1403.865		
	Total	218889.4	145			
Age	Between Groups	2325.296	7	332.185	1.786	.093
	Within Groups	29379.58	158	185.947		
	Total	31704.87	165			
Education Degree	Between Groups	10.665	7	1.524	1.027	.415
	Within Groups	232.947	157	1.484		
	Total	243.612	164			
Household Income	Between Groups	28.088	7	4.013	.816	.575
	Within Groups	688.094	140	4.915		
	Total	716.182	147			

In order to look into these differences shown above, Means Plot was run for dichotomous variables (e.g., gender) and ordinal variables (e.g., age group), and Frequency Crosstab was run for categorical variables (e.g., working status).

For both patients and companions, the Means Plots (See Figure 7) show that 1) in average, head-neck and lung cancers are more recently diagnosed than the rest (*P* = .000) ; 2) there are more females in breast, G.I., and gynecological groups than the rest (*P* = .001); 3) cancer groups of breast, G.I., head and neck, and “other” are averagely younger than the rest (*P* = .011); 4) the household income levels of breast, G.I., and gynecological groups are averagely higher than the rest (*P* = .000); 5) fewer patients and companions in H.M. group have children than the rest (*P* = .019); 6) and finally, patients and companions in breast cancer group have the most percentage of Internet access, and those who are in head-neck and lung cancer groups have the least (*P* = .017). The Frequency Crosstab (See Table 16) shows that the majority of patients and companions in breast, G.I., Gynecological, head and neck, and H.M. groups are still working at present, but those who are in cancer groups of lung, U.G. and “other” are mainly retired (*P* = .020).

For patients, the Means Plots (See Figure 8) show that: 1) lung cancer patients are more recently diagnosed than the rest (*P* = .005); 2) breast and gynecological groups have only female patients, while the rest have more males than females (*P* = .000).

For companions, the Means Plots (See Figure 9) show that: 1) the paired patients of companions in head-neck and lung groups are more recently diagnosed (*P* = .017); 2) the majority of companions in G.I., head and neck, H.M., Lung, and U.G. groups are females, while the majority of companions in groups of breast, gynecological, and “other” are males (*P* = .000). The Frequency Crosstab (See Table 17) show that although the majority of companions are still working at present, those who are in lung cancer group are mainly retired and those in “other” are almost half working and half retired (*P* = .002).

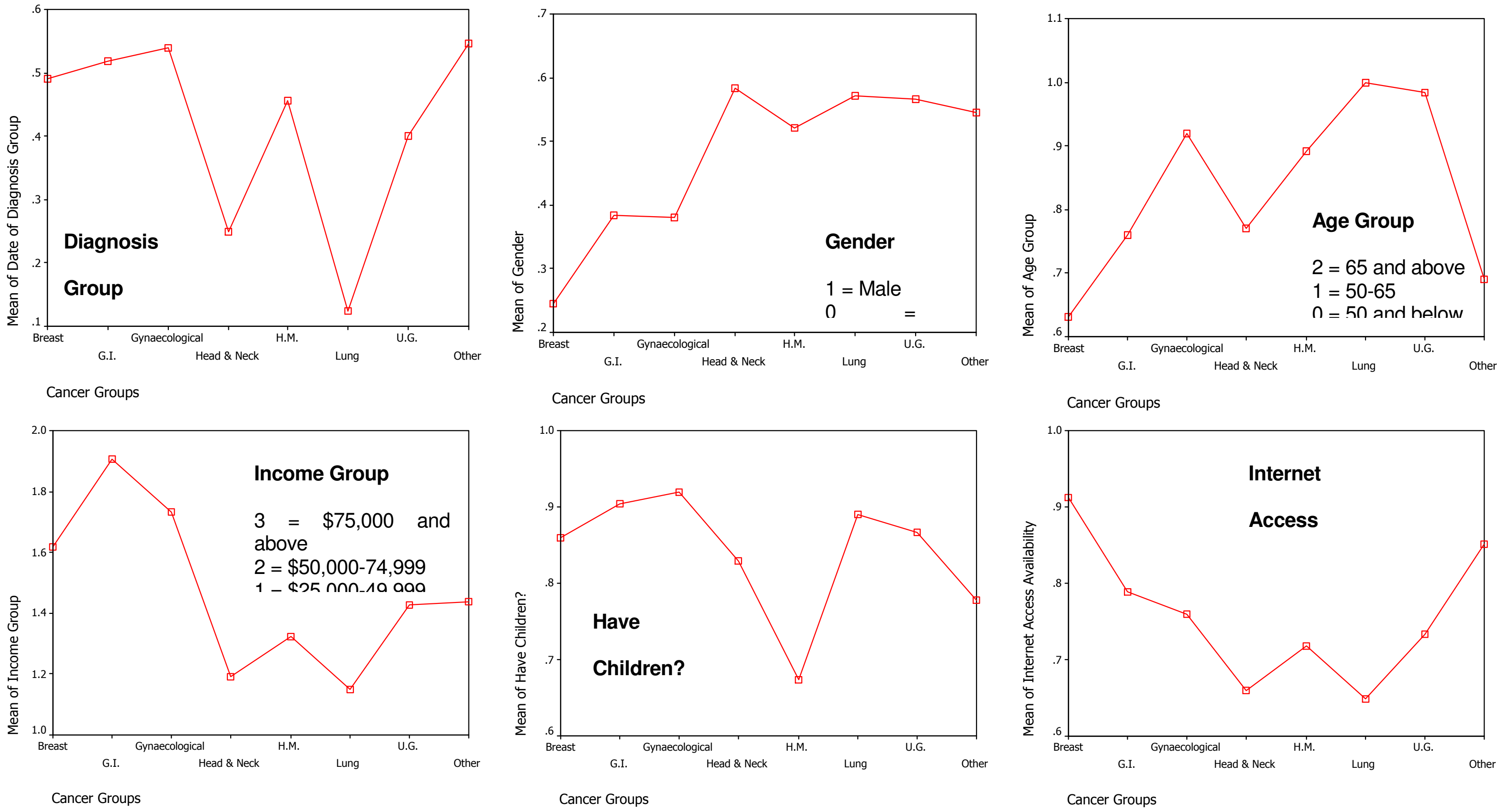


Figure 7: Means Plots by Cancer Groups (Overall)

Table 16: Frequency Crosstab for Working Status by Cancer Groups (Overall)

			Cancer Groups								Total
			Breast	G.I.	Gynaecological	Head & Neck	H.M.	Lung	U.G.	Other	
Working Status	Working	Count	27	17	20	20	14	22	19	16	155
		% within Cancer Groups	52.9%	36.2%	46.5%	46.5%	35.9%	44.0%	35.8%	30.2%	40.9%
	Full-time Sick Leave	Count	5	7	5	9	7	2	4	6	45
		% within Cancer Groups	9.8%	14.9%	11.6%	20.9%	17.9%	4.0%	7.5%	11.3%	11.9%
	Retired	Count	10	12	10	10	12	24	25	22	125
		% within Cancer Groups	19.6%	25.5%	23.3%	23.3%	30.8%	48.0%	47.2%	41.5%	33.0%
	Unemployed	Count	9	11	8	4	6	2	5	9	54
		% within Cancer Groups	17.6%	23.4%	18.6%	9.3%	15.4%	4.0%	9.4%	17.0%	14.2%
Total		Count	51	47	43	43	39	50	53	53	379
		% within Cancer Groups	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

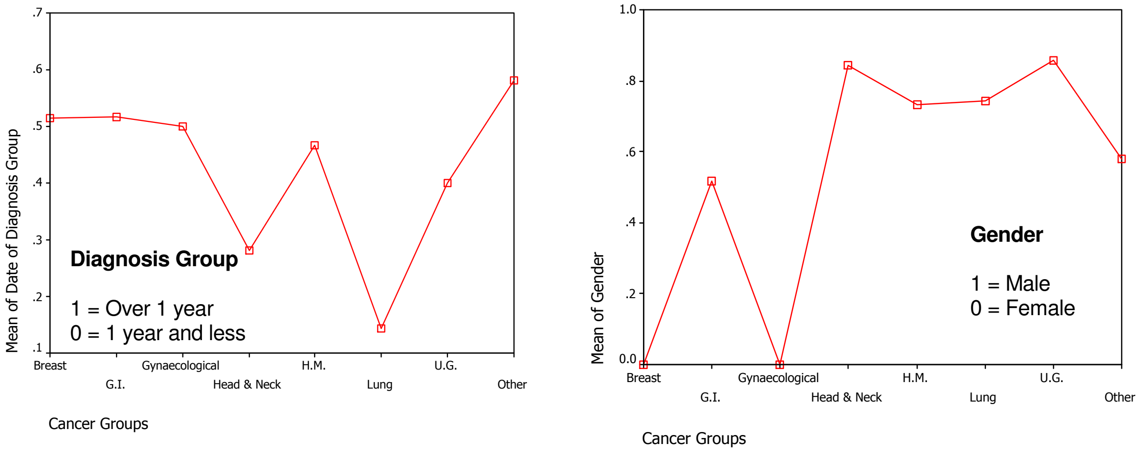


Figure 8: Means Plots by Cancer Groups (Patient)

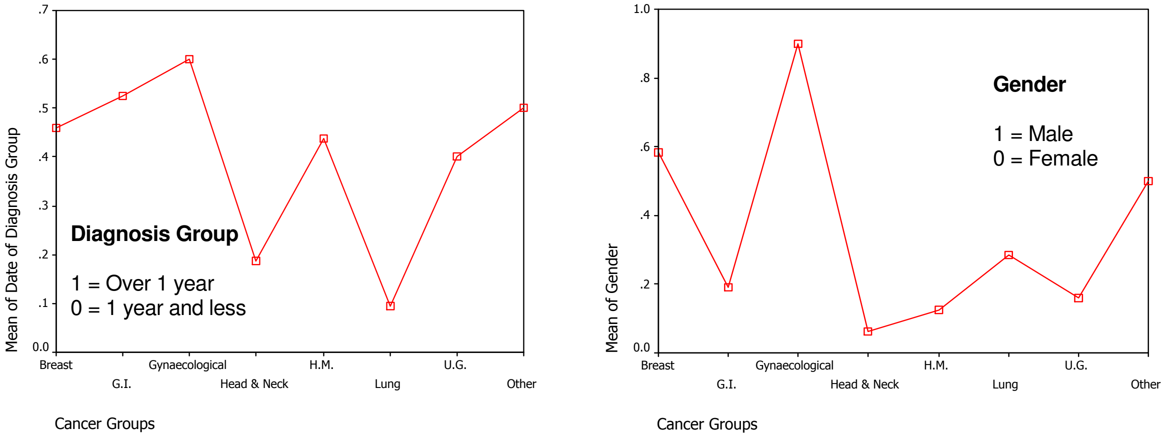


Figure 9: Means Plots by Cancer Groups (Companion)

Table 17: Frequency Crosstab for Working Status by Cancer Groups (Companion)

			Cancer Groups								
			Breast	G.I.	Gynaecological	Head & Neck	H.M.	Lung	U.G.	Other	Total
Working Status	Working	Count	17	11	14	12	8	8	11	10	91
		% within Cancer Groups	77.3%	57.9%	77.8%	75.0%	57.1%	42.1%	50.0%	45.5%	59.9%
	Full-time Sick Leave	Count					1				1
		% within Cancer Groups					7.1%				.7%
	Retired	Count	4	1	4	2	4	10	9	10	44
		% within Cancer Groups	18.2%	5.3%	22.2%	12.5%	28.6%	52.6%	40.9%	45.5%	28.9%
	Unemployed	Count	1	7		2	1	1	2	2	16
		% within Cancer Groups	4.5%	36.8%		12.5%	7.1%	5.3%	9.1%	9.1%	10.5%
Total		Count	22	19	18	16	14	19	22	22	152
		% within Cancer Groups	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

In summary, patients and companions by different cancer groups share some similarities: patients in each cancer group are mostly receiving treatments, their companions are mostly spouses and children, and both are mostly white, have insurance, are married or in regular partnership, have children, owe computers and having Internet accesses. There are also some distinctive demographic characteristics of patients and companions by cancer groups as follows:

1) The breast cancer group are mainly aged either less than 50 (45.6%) or 50-65 (45.6%), college educated (with 43.9% having the bachelor's degree at least and 33.3% some college), still working (52.9%), with income either between $25,000-49,999 (34.5%) or more than $75,000 (32.7%). Patients in this group are all females, mainly aged 50-65 (54.5%). While companions in this group are over half males (58.3%), mainly aged less than 50 (54.2%).

2) The G.I. cancer group is mainly high educated (with 34.6% having the bachelor's degree at least and 26.9% some college). Patients in this group are balanced in gender, mainly retired (39.3%), with income more than $75,000 (51.2%). While companions in this group are mainly females (81.0%), still working (57.9).

3) The gynecological cancer group are mainly aged 50-65 (48.0%), high school (with diploma) educated (36%), with income more than $50,000 (62.2%). Patients in this group are all females, high school (with diploma) educated (50%), unemployed (32.0%). While companions in this group are mainly males (90.0%), some college educated (45%), still working (77.8%).

4) The head and neck cancer group are mainly aged 50-65 (56.3%), some college (31.9%) or high school (with diploma) (29.8%) educated, with income less than $50,000 (64.3%). Patients in this group are mainly diagnosed within a year (71.9%), males (84.4%), in full-time sick leave (33.3%). While companions in this group are mainly females (93.8%), still working (75.0%).

5) The H.M. cancer group are mainly aged either less than 50 (37.0%) or 50-65 (37.0%), high school (with diploma) educated (32.6%), with income less than $25,000 (32.4%). Patients in this group are mainly males (73.3%), retired (32.0%). While companions in this group are mainly females (87.5%), still working (57.1%).

6) The lung cancer group are mainly aged 50-65 (55.6%), high school (with diploma) educated (37.5%), either working (44.0%) or retired (48.0%), with income less than $25,000 (40.4%). Patients in this group are mainly diagnosed within a year (87.5%), males (74.3%), either working (45.2%) or retired (45.2%). While companions in this group are mainly females (71.4%), retired (52.6%).

7) The U.G. cancer group are mainly aged 50-65 (57.6%), high school (with diploma) educated (35.0%), retired (47.2%), with income between $25,000-49,000. Patients in this group are mainly males (85.7%), retired (51.6%). While companions in this group are mainly females (84.0%), still working (50.0%).

8) The other cancers group are balanced in gender, mainly aged less than 50 (50.9%), either college (with 37.8% having the bachelor's degree at least and 24.0% some college) or high school (with diploma) educated (32.1%), retired (41.5%), with income either less than $25,000 (29.2%) or between $50,000-74,999 (27.1%). Patients in this group are mainly retired (38.7%). While companions in this group are either working (45.5%) or retired (45.5%).

Hypothesis Testing

After completing the sample demographics section, the data collected were analyzed to test the hypotheses formulated. All of the statistical analyses were analyzed by using SPSS or Excel Data Analysis.

Hypothesis 1

The first hypothesis proposed that cancer patients believe that information is beneficial for them to cope with cancer by increasing their involvement in decision-making (H1Pa), increasing their satisfaction with treatment choices (H1Pb), improving their ability to cope during the diagnosis, treatment, and post-treatment phases (H1Pc), reducing their anxiety (H1Pd), and improving the communication among family members (H1Pe). It also proposed that companions have the same belief as their paired patients about these information benefits (H1Ca, H1Cb, H1Cc, H1Cd, and H1Ce).

Frequency Table was run for all the information benefits and Z-test (which is for comparing two proportions) was run to compare the differences between patients and companions (See Table 18). The Frequency Table shows that, 1) almost all (over 95%) of patients and companions agree that information increases their involvement in decision making and satisfaction with treatment choices, and improves their abilities to cope with cancer and communication among family members; 2) the majority (over 77%) of patients and companions agree that information reduces their anxiety and mood disturbance.

Since there is noticeable drop in the number of either patients or companions who agree that information can reduce anxiety, Z-test was run to see whether this drop is statistically significant (See Table 19). It shows, for both patients and companions, the drop is significant (P = .000), which means that strong evidence exists of an opinion difference from other benefits, with opinions more negative towards whether information can reduce anxiety.

Table 18: Frequency and Z-test for Information Benefits

Information Benefits	Overall		Patient		Companion		Patient vs. Companion	
	N	Yes %	N	Yes %	N	Yes %	% Differences	Sig.
1 Increase involvement in decision making	405	98.3%	244	98.0%	161	98.8%	0.8%	.192
2 Increase satisfaction with treatment choices	405	95.8%	244	95.9%	161	95.7%	0.2%	.444
3 Improve ability to cope with cancer	404	96.5%	243	96.7%	161	96.3%	0.4%	.378
4 Reduce anxiety	405	78.0%	244	77.0%	161	79.5%	2.5%	.195
5 Improve communication among family members	405	95.1%	244	94.3%	161	96.3%	2.0%	.095

Table 19: Z-test for Information Benefits (Reduce Anxiety vs. Other Benefits)

Information Benefits	Differences from Reduce Anxiety (Sig.)		
	Overall	Patient	Companion
Increase involvement in decision making	***.000***	***.000***	***.000***
Increase satisfaction with treatment choices	***.000***	***.000***	***.000***
Improve ability to cope with cancer	***.000***	***.000***	***.000***
Improve communication among family members	***.000***	***.000***	***.000***

Table 18 also shows that there is no significant difference of opinions between patients and companions ($P > .050$). However, it is unknown that whether there is any difference between a patient and a companion who are paired with each other. Therefore, Paired Sample T-test was run for each pair of patient and companion after restructuring the database by aggregating companions' cases to their paired patients' cases. The Paired Samples T-tests (See Table 20) show that there is no significant difference between paired patients and companions for all the five information benefits, which confirms the results of the previous Z-test.

Table 20: Paired Samples T-test (Patient vs. Companion)

Information Benefits	Patient vs. Companion (Paired)	
	N	Sig. (2-tailed)
1 Increase involvement in decision making	160	.565
2 Increase satisfaction with treatment choices	160	.740
3 Improve ability to cope with cancer	159	1.000
4 Reduce anxiety	160	.249
5 Improve communication among family members	160	.565

Hypothesis 2

The second hypothesis proposed that there is a significant relationship between stages of cancer disease and types of medical topics searched by cancer patients: they search for different medical topics in different stages (H2Pa); and those who are in the same stage search for similar medical information (H2Pb). It also proposed that companions search for same topics as cancer patients through different stages (H2C).

Before testing the hypothesis, it is helpful to first look at the ranking of topics sought by patients and companions in the past and future. On the whole (See Table 20), the most frequently sought topics in the past were diagnosis and treatment, drugs and side effects, and coping with cancer, which are also the most possibly sought topics in the future. However, from the 4th ranked topics, there are some changes from the past to the future: 1) topics about nutrition, complementary and alternative medicine, clinical trials and genetics services, cancer prevention/genetics/causes, and pain management are ranked at least one place higher; 2) while topics about cancer literature, cancer hospitals, and patient experiences are ranked at least on place lower; 3) topics about oncologists, insurance/financial assistance, support and resources, and cancer biology remain the same. Similar rankings are found for patients (See Table 21) and companions (See Table 22). Either in the past or in the future, patients seem to care more about nutrition, and complementary and alternative medicine, while companions seem to care more about cancer literature, and clinical trials and genetics services.

To further test whether there are significant differences either between patient and companion or between current and future, Z-test was run for the comparison between "yes" proportions and Paired Samples T-test was run for the comparison within each case or each pair of patient and companion.

The Z-tests (See Table 23) show that: 1) one the whole, there are significant differences between current and future topics for diagnosis and treatment (*P* = .000, with 12.8% down), doping with cancer (*P* = .009, with 5.7% down), and cancer hospitals (*P* = .001, with 8.1% down); 2) for patients, there are significant differences for diagnosis and treatment (*P* = .000, with 14.5% down), coping with cancer (*P* = .029, with 5.9% down), cancer hospitals (*P* = .002, with 5.9% down), and cancer literature (*P* = .027, with 8.6% down); 3) for companions, there are significant differences for diagnosis and treatment (*P* = .002, with 10.2% down), cancer hospitals (*P* = .029, with 7.3% down), and insurance/financial assistance (*P* = .038, with 6.0% up); 4) for the comparison between patients and companions, there is a significant difference of current topics for diagnosis and treatment (*P* = .006, with 9.4% less companions than patients), and there are significant differences of future topics for cancer prevention/genetics/causes (*P* = .045, with 8.1% more companions than patients) and insurance/financial assistance (*P* = .022, with 8.5% more companions than patients).

Table 21: Topics Ranking (Overall, N=424)

Current			Future		
Ranking	Topics	Yes %	Ranking	Topics	Yes %
1	Diagnosis and Treatment	82.2%	1	Diagnosis and Treatment	69.4%
2	Drugs and Side Effects	58.4%	2	Drugs and Side Effects	55.8%
3	Coping with Cancer	54.6%	3	Coping with Cancer	48.9%
4	Cancer Literature	45.4%	4	Nutrition	44.4%
5	Nutrition	45.1%	5	Cancer Literature	42.0%
6	Cancer Hospitals	43.7%	6	Complementary and Alternative Medicine	38.2%
7	Complementary and Alternative Medicine	39.0%	7	Clinical Trials and Genetics Services	37.3%
8	Oncologists	39.0%	8	Oncologists	36.3%
9	Clinical Trials and Genetics Services	38.7%	9	Cancer Prevention/Genetics/Causes	36.1%
10	Cancer Prevention/Genetics/Causes	34.2%	10	Cancer Hospitals	35.6%
11	Patient Experiences	31.9%	11	Pain Management	32.1%
12	Pain Management	29.5%	12	Patient Experiences	30.4%
13	Insurance/Financial Assistance	23.5%	13	Insurance/Financial Assistance	23.8%
14	Support and Resources	21.1%	14	Support and Resources	22.6%
15	Cancer Biology	20.2%	15	Cancer Biology	20.7%

Table 22: Topics Ranking (Patient, N=257)

Current			Future		
Ranking	**Topics**	**Yes %**	**Ranking**	**Topics**	**Yes %**
1	Diagnosis and Treatment	85.9%	1	Diagnosis and Treatment	71.4%
2	Drugs and Side Effects	55.7%	2	Drugs and Side Effects	52.9%
3	Coping with Cancer	52.2%	3	Coping with Cancer	46.3%
4	Nutrition	45.5%	4	Nutrition	44.3%
5	Cancer Literature	45.1%	5	Cancer Literature	39.2%
6	Cancer Hospitals	43.1%	6	Complementary and Alternative Medicine	38.4%
7	Complementary and Alternative Medicine	39.6%	7	Clinical Trials and Genetics Services	36.5%
8	Oncologists	38.4%	8	Oncologists	34.5%
9	Clinical Trials and Genetics Services	37.6%	9	Cancer Hospitals	34.5%
10	Cancer Prevention/Genetics/Causes	32.2%	10	Cancer Prevention/Genetics/Causes	32.9%
11	Patient Experiences	30.6%	11	Pain Management	32.5%
12	Pain Management	29.0%	12	Patient Experiences	28.6%
13	Insurance/Financial Assistance	23.9%	13	Support and Resources	21.6%
14	Support and Resources	19.6%	14	Insurance/Financial Assistance	20.4%
15	Cancer Biology	19.2%	15	Cancer Biology	18.8%

Table 23: Topics Ranking (Companion, N=167)

Current			Future		
Ranking	**Topics**	**Yes %**	**Ranking**	**Topics**	**Yes %**
1	Diagnosis and Treatment	76.5%	1	Diagnosis and Treatment	66.3%
2	Drugs and Side Effects	62.7%	2	Drugs and Side Effects	60.2%
3	Coping with Cancer	58.4%	3	Coping with Cancer	53.0%
4	Cancer Literature	45.8%	4	Cancer Literature	46.4%
5	Nutrition	44.6%	5	Nutrition	44.6%
6	Cancer Hospitals	44.6%	6	Cancer Prevention/Genetics/Causes	41.0%
7	Clinical Trials and Genetics Services	40.4%	7	Oncologists	39.2%
8	Oncologists	39.8%	8	Clinical Trials and Genetics Services	38.6%
9	Complementary and Alternative Medicine	38.0%	9	Complementary and Alternative Medicine	38.0%
10	Cancer Prevention/Genetics/Causes	37.3%	10	Cancer Hospitals	37.3%
11	Patient Experiences	33.9%	11	Patient Experiences	33.1%
12	Pain Management	30.1%	12	Pain Management	31.3%
13	Support and Resources	23.5%	13	Insurance/Financial Assistance	28.9%
14	Insurance/Financial Assistance	22.9%	14	Support and Resources	24.1%
15	Cancer Biology	21.7%	15	Cancer Biology	24.1%

Table 24: Z-test for Topics Comparison (Patient vs. Companion and Current vs. Future)

Topics	Overall (N=424)				Patient (N=257)				Companion (N=167)				Patient vs. Companion			
	Current	Future	Differences		Current	Future	Differences		Current	Future	Differences		Current		Future	
	Yes %	Yes %	% Differences	Sig.	Yes %	Yes %	% Differences	Sig.	Yes %	Yes %	% Differences	Sig.	% Differences	Sig.	% Differences	Sig.
1 Diagnosis and Treatment	82.2%	69.4%	-12.8%	***.000***	85.9%	71.4%	-14.5%	***.000***	76.5%	66.3%	-10.2%	***.002***	-9.4%	***.006***	-5.1%	.136
2 Complementary and Alternative Medicine	39.0%	38.2%	-0.8%	.367	39.6%	38.4%	-1.2%	.348	38.0%	38.0%	0.0%	.500	-1.6%	.382	-0.4%	.460
3 Clinical Trials and Genetics Services	38.7%	37.3%	-1.4%	.278	37.6%	36.5%	-1.1%	.356	40.4%	38.6%	-1.8%	.309	2.8%	.281	2.1%	.330
4 Coping with Cancer	54.6%	48.9%	-5.7%	***.009***	52.2%	46.3%	-5.9%	***.029***	58.4%	53.0%	-5.4%	.081	6.2%	.106	6.7%	.089
5 Pain Management	29.5%	32.1%	2.6%	.123	29.0%	32.5%	3.5%	.111	30.1%	31.3%	1.2%	.367	1.1%	.405	-1.2%	.382
6 Cancer Biology	20.2%	20.9%	0.7%	.359	19.2%	18.8%	-0.4%	.436	21.7%	24.1%	2.4%	.230	2.5%	.264	5.3%	.095
7 Drugs and Side Effects	58.4%	55.8%	-2.6%	.140	55.7%	52.9%	-2.8%	.184	62.7%	60.2%	-2.5%	.242	7.0%	.076	7.3%	.069
8 Nutrition	45.1%	44.4%	-0.7%	.386	45.5%	44.3%	-1.2%	.348	44.6%	44.6%	0.0%	.500	-0.9%	.421	0.3%	.476
9 Patient Experiences	31.9%	30.4%	-1.5%	.251	30.6%	28.6%	-2.0%	.242	33.9%	33.1%	-0.8%	.421	3.3%	.239	4.5%	.164
10 Cancer Prevention/Genetics/Causes	34.2%	36.1%	1.9%	.206	32.2%	32.9%	0.7%	.405	37.3%	41.0%	3.7%	.164	5.1%	.140	8.1%	***.045***
11 Oncologists	39.0%	36.3%	-2.7%	.125	38.4%	34.5%	-3.9%	.097	39.8%	39.2%	-0.6%	.421	1.4%	.386	4.7%	.164
12 Cancer Hospitals	43.7%	35.6%	-8.1%	***.001***	43.1%	34.5%	-8.6%	***.002***	44.6%	37.3%	-7.3%	***.029***	1.5%	.382	2.8%	.278
13 Support and Resources	21.1%	22.6%	1.5%	.227	19.6%	21.6%	2.0%	.215	23.5%	24.1%	0.6%	.429	3.9%	.169	2.5%	.274
14 Insurance/Fancial Assistance	23.5%	23.8%	0.3%	.440	23.9%	20.4%	-3.5%	.089	22.9%	28.9%	6.0%	***.038***	-1.0%	.421	8.5%	***.022***
15 Cancer Literature	45.4%	42.0%	-3.4%	.079	45.1%	39.2%	-5.9%	***.027***	45.8%	46.4%	0.6%	.436	0.7%	.444	7.2%	.071

To test more specifically if there are significant differences for one person between current and future, Paired Sample T-test was run within each case. The Paired Samples T-tests (See Table 25) show that: 1) on the whole, one is highly possible to change his or her behavior in the future when searching topics on diagnosis and treatment (*P* = .000), coping with cancer (*P* = .006), or cancer hospitals (*P* = .000), with less possibilities of searching these topics again in the future (Also See Table 24); 2) for patients, one is highly possible to change his or her behavior in the future when searching topics on diagnosis and treatment (*P* = .000), coping with cancer (*P* = .019), oncologists (*P* = .041), cancer hospitals (*P* = .000), insurance/financial assistance (*P* = .029), and cancer literature (*P* = .007), with a low possibility of searching these topics again in the future (Also See Table 24); 3) for companions, one is highly possible to change his or her behavior in the future when searching topics on diagnosis and treatment (*P* = .005), with a low possibility of searching these topics again in the future (Also See Table 24).

Table 25: Paired Samples T-test for Topics Comparison (Current vs. Future)

Topics	Current vs. Future		
	Overall Sig. (N=421)	Patient Sig. (N=255)	Companion Sig. (N=166)
1 Diagnosis and Treatment	***.000***	***.000***	***.005***
2 Complementary and Alternative Medicine	.669	.578	1.000
3 Clinical Trials and Genetics Services	.397	.565	.533
4 Coping with Cancer	***.006***	***.019***	.129
5 Pain Management	.145	.106	.696
6 Cancer Biology	.267	.402	.395
7 Drugs and Side Effects	.159	.209	.467
8 Nutrition	.686	.578	1.000
9 Patient Experiences	.366	.267	.836
10 Cancer Prevention/Genetics/Causes	.249	.671	.240
11 Oncologists	.131	***.041***	.853
12 Cancer Hospitals	***.000***	***.000***	.051
13 Support and Resources	.355	.298	.819
14 Insurance/Financial Assistance	.884	***.029***	.068
15 Cancer Literature	.061	***.007***	.842

To test more specifically whether there are significant differences in topics between a patient and a companion who are paired with each other, Paired Sample T-test was run for each pair of patient and companion. The Paired Samples T-tests (See Table 26) show that: 1) in the past, the paired patient and companion behaved differently in searching topics on diagnosis and treatment (*P* = .035), and coping with cancer (*P* = .026), with a high possibility that patient usually searched for diagnosis and treatment while the companion searched for coping with cancer (Also See Table 24); 2) in the future, the pared patient and companion will probably behave differently in searching topics on coping with cancer (*P* = .029), drugs and side effects (*P* = .036), cancer prevention/genetics/causes (*P* = .018), and insurance/financial assistance (*P* = .032), with a high possibility that the companion will search for these topics but the patient will not (Also See Table 24).

Table 26: Paired Samples T-test for Topics Comparison (Patient vs. Companion)

Topics	Patient vs. Companion (Paired) Current Sig. (N=164)	 Future Sig. (N=164)
1 Diagnosis and Treatment	***.035***	.387
2 Complementary and Alternative Medicine	.537	.800
3 Clinical Trials and Genetics Services	.790	.803
4 Coping with Cancer	***.026***	***.029***
5 Pain Management	.486	.902
6 Cancer Biology	.548	.935
7 Drugs and Side Effects	.063	***.036***
8 Nutrition	.734	1.000
9 Patient Experiences	.234	.226
10 Cancer Prevention/Genetics/Causes	.090	***.018***
11 Oncologists	.543	.379
12 Cancer Hospitals	.903	.806
13 Support and Resources	.249	.407
14 Insurance/Financial Assistance	1.000	***.032***
15 Cancer Literature	.347	.104

To test whether patients or companions searched for different topics in different stages, Chi-square Test was run (See Table 27). The results show that: 1) on the whole, only topics about diagnosis and treatment (*P* = .027), and cancer hospitals (*P* = .028) were influenced by different stages; 2) for patients, the same topics were influenced by stages (*P* = .014, and *P* = .020 respectively); 3) for companions, only the topic of insurance/financial assistance was influenced by stages (*P* = .013).

Table 27: Chi-square Tests for Topics by Stage

Topics Searched	Differences by Stage (Asymp Sig. 2-sided)		
	Overall (N=424)	Patient (N=257)	Companion (N=167)
1 Diagnosis and Treatment	***.027***	***.014***	.680
2 Complementary and Alternative Medicine	.639	.245	.428
3 Clinical Trials and Genetics Services	.709	.856	.387
4 Coping with Cancer	.115	.068	.792
5 Pain Management	.260	.386	.458
6 Cancer Biology	.520	.094	.248
7 Drugs and Side Effects	.965	.852	.917
8 Nutrition	.775	.451	.580
9 Patient Experiences	.703	.105	.121
10 Cancer Prevention/Genetics/Causes	.168	.060	.902
11 Oncologists	.959	.403	.313
12 Cancer Hospitals	***.028***	***.020***	.536
13 Support and Resources	.958	.436	.314
14 Insurance/Financial Assistance	.826	.132	***.013***
15 Cancer Literature	.552	.225	.531

To look into the above differences, Means Plots were run, showing that: 1) on the whole (See Figure 10), patients and companions searched for information about diagnosis, treatment (*P* = .027) and cancer hospitals (*P* = .028) more frequently in follow-up than in treatment receiving stage; 2) for patients (See Figure 11), the same as the overall (*P* = .014, and *P* = .020 respectively); and 3) for companions (See Figure 12), they search for information about insurance/financial assistance more frequently in patients' treatment than in follow-up stage (*P* = .013).

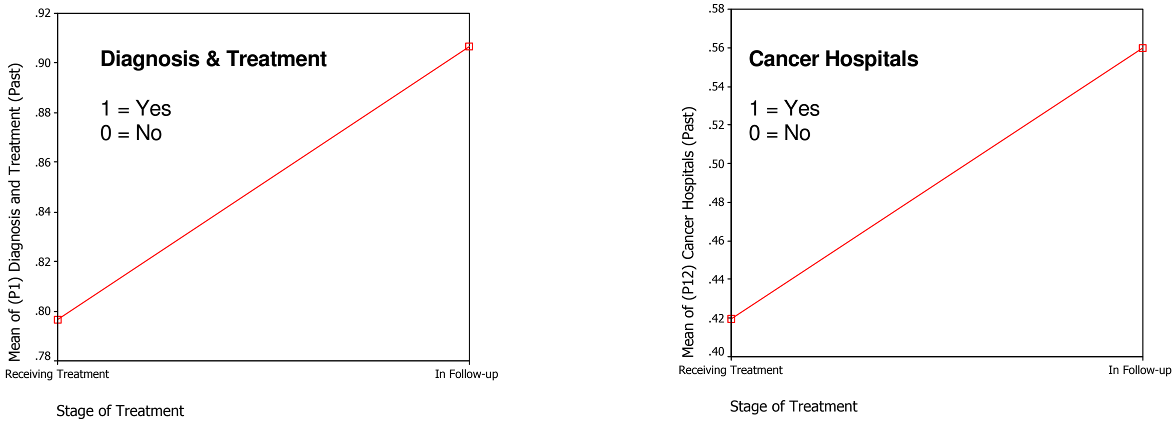


Figure 10: Means Plots by Stage (Overall)

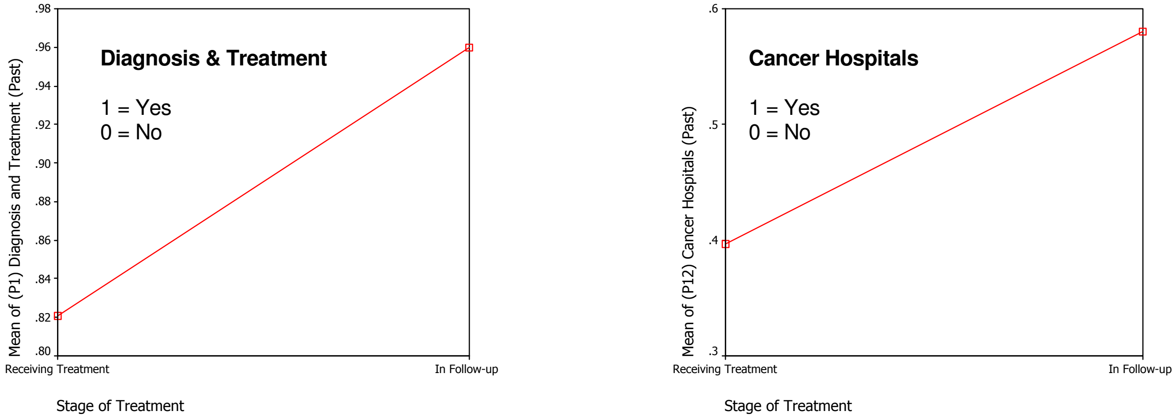


Figure 11: Means Plots by Stage (Patient)

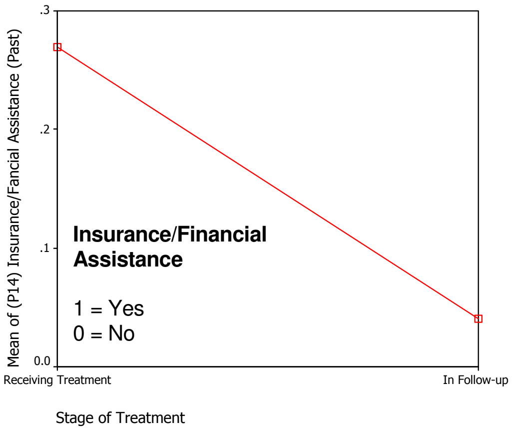


Figure 12: Means Plots by Stage (Companion)

Hypothesis 3

The third hypothesis proposed that cancer patients follow the same construct of information source horizon as the general population in the past (H3Pa) and future (H3Pb). It also proposed that companions follow the same construct of information source horizon as cancer patients in the past (H3Ca) and future (H3Cb).

Before testing the hypothesis, it is helpful to first look at the ranking of sources used by patients and companions in the past and future. On the whole (See Table 28), the most frequently used sources in the past were talking with physician or physician's assistant, talking with nurse or other health professionals, talking with relatives, friends, and acquaintances, medical leaflets or pamphlets, and books, which are also the most possibly sources in the future. However, from the

6th ranked sources, there are some changes from the past to the future: 1) sources including Internet or medical websites, talking with a support group, educational programs by HMO or hospital, email from physician or physician's assistant, email from nurse or other health professional, and message board are ranked at least one place higher; 2) while sources including talking with other patients, email from relatives, friends, and acquaintances, national/local medical information services, films/movies, audio/video tapes, and telephone/helpline are ranked at least on place lower; 3) sources including newspapers/magazines, TV/radio, medical journals, narratives, email or chat-room with a support group, and email or chat-room with other patients remain the same. Similar rankings are found for patients (See Table 29) and companions (See Table 30). However, either in the past or in the future, patients seem to talk with other patients more, while companions seem to use Internet more often.

Table 28: Overall Medical Information Source Ranking

Current				Future			
Ranking	Source	Yes % (N=424)	Quality Mean	Ranking	Source	Yes % (N=424)	Quality Mean
1	Talking with Physician or Physican's Assistant	97.2%	6.22	1	Talking with Physician or Physican's Assistant	84.0%	6.39
2	Talking with Nurse or Other Health Professionals	83.7%	6.01	2	Talking with Nurse or Other Health Professionals	69.6%	6.15
3	Talking with Relatives, Friends, and Acquaintances	66.7%	4.84	3	Talking with Relatives, Friends, and Acquaintances	47.9%	5.04
4	Medical Leaflets or Pamphlets	54.7%	5.53	4	Medical Leaflets or Pamphlets	41.7%	5.86
5	Books	51.7%	5.61	5	Books	40.8%	5.83
6	Talking with Other Patients	49.1%	5.02	6	Internet or Medical Websites	39.9%	5.21
7	Internet or Medical Websites	46.2%	5.74	7	Talking with Other Patients	39.9%	5.82
8	Newspapers/Magazines	37.5%	4.84	8	Newspapers/Magazines	28.5%	4.96
9	TV/Radio	27.1%	4.47	9	TV/Radio	21.7%	4.57
10	Medical Journals	22.4%	5.96	10	Medical Journals	20.3%	6.07
11	Narratives	17.0%	5.16	11	Narratives	14.9%	5.43
12	Email from Relatives, Friends, and Acquaintances	16.0%	4.79	12	Talking with a Support Group	14.4%	5.17
13	National/Local Medical Information Services	15.1%	5.67	13	Email from Relatives, Friends, and Acquaintances	14.4%	4.97
14	Talking with a Support Group	13.9%	4.67	14	National/Local Medical Information Services	13.2%	5.98
15	Films/Movies	9.7%	5.19	15	Educational Programs by HMO or Hospital	10.4%	5.89
16	Educational Programs by HMO or Hospital	9.2%	5.33	16	Email from Physician or Physician's Assistant	9.7%	6.02
17	Email from Physician or Physician's Assistant	9.0%	5.67	17	Email from Nurse or Other Health Professionals	6.8%	6.23
18	Audio/Video Tapes	8.7%	5.29	18	Films/Movies	6.4%	5.24
19	Telephone/Helpline	6.8%	5.40	19	Message Board	5.9%	5.54
20	Email from Nurse or Other Health Professionals	6.6%	5.71	20	Audio/Video Tapes	5.7%	5.17
21	Message Board	6.6%	5.17	21	Telephone/Helpline	5.2%	5.90
22	Email or Chat-room with a Support Group	4.7%	4.80	22	Email or Chat-room with a Support Group	5.0%	5.38
23	Email or Chat-room with Other Patients	3.1%	4.92	23	Email or Chat-room with Other Patients	4.2%	5.81

Table 29: Patient's Medical Information Source Ranking

Current				Future			
Ranking	Source	Yes % (N=257)	Quality Mean	Ranking	Source	Yes % (N=257)	Quality Mean
1	Talking with Physician or Physican's Assistant	98.1%	6.29	1	Talking with Physician or Physican's Assistant	85.2%	6.45
2	Talking with Nurse or Other Health Professionals	83.7%	6.06	2	Talking with Nurse or Other Health Professionals	69.3%	6.21
3	Talking with Relatives, Friends, and Acquaintances	65.8%	4.87	3	Talking with Relatives, Friends, and Acquaintances	47.5%	5.01
4	Talking with Other Patients	51.8%	5.12	4	Talking with Other Patients	43.2%	5.23
5	Medical Leaflets or Pamphlets	50.2%	5.59	5	Books	40.9%	5.98
6	Books	49.8%	5.56	6	Medical Leaflets or Pamphlets	38.5%	5.81
7	Internet or Medical Websites	39.3%	5.68	7	Internet or Medical Websites	33.9%	5.78
8	Newspapers/Magazines	37.7%	4.72	8	Newspapers/Magazines	29.2%	4.85
9	TV/Radio	26.8%	4.44	9	TV/Radio	21.8%	4.6/
10	Medical Journals	21.0%	5.83	10	Medical Journals	19.8%	5.92
11	Narratives	19.1%	5.10	11	Narratives	16.0%	5.43
12	Talking with a Support Group	16.3%	4.64	12	Talking with a Support Group	14.8%	5.05
13	Email from Relatives, Friends, and Acquaintances	15.2%	4.61	13	Email from Relatives, Friends, and Acquaintances	12.1%	4.81
14	National/Local Medical Information Services	14.8%	5.39	14	National/Local Medical Information Services	12.1%	5.94
15	Films/Movies	9.7%	5./8	15	Educational Programs by HMO or Hospital	10.9%	5.38
16	Educational Programs by HMO or Hospital	9.3%	5.23	16	Email from Physician or Physician's Assistant	7.0%	5.96
17	Audio/Video Tapes	9.3%	5.31	17	Audio/Video Tapes	6.2%	5.33
18	Email from Physician or Physician's Assistant	7.8%	5.68	18	Films/Movies	5.8%	6.21
19	Telephone/Helpline	7.0%	5.11	19	Email from Nurse or Other Health Professionals	5.4%	5.64
20	Email from Nurse or Other Health Professionals	6.2%	5.21	20	Message Board	5.4%	6.17
21	Message Board	6.2%	5.31	21	Telephone/Helpline	4.7%	5.79
22	Email or Chat-room with a Support Group	5.1%	4.85	22	Email or Chat-room with a Support Group	4.3%	5.58
23	Email or Chat-room with Other Patients	3.5%	5.11	23	Email or Chat-room with Other Patients	2.3%	6.67

Table 30: Companion's Medical Information Source Ranking

Current				Future			
Ranking	**Source**	**Yes % (N=167)**	**Quality Mean**	**Ranking**	**Source**	**Yes % (N=167)**	**Quality Mean**
1	Talking with Physician or Physican's Assistant	95.8%	6.10	1	Talking with Physician or Physican's Assistant	82.0%	6.28
2	Talking with Nurse or Other Health Professionals	83.8%	5.93	2	Talking with Nurse or Other Health Professionals	70.1%	6.07
3	Talking with Relatives, Friends, and Acquaintances	68.3%	4.79	3	Internet or Medical Websites	49.1%	5.86
4	Medical Leaflets or Pamphlets	61.7%	5.47	4	Talking with Relatives, Friends, and Acquaintances	48.5%	5.10
5	Internet or Medical Websites	56.9%	5.81	5	Medical Leaflets or Pamphlets	46.7%	5.70
6	Books	54.5%	5.69	6	Books	40.7%	5.87
7	Talking with Other Patients	44.9%	4.85	7	Talking with Other Patients	34.7%	5.17
8	Newspapers/Magazines	37.1%	5.03	8	Newspapers/Magazines	27.5%	5.15
9	TV/Radio	27.5%	4.52	9	TV/Radio	21.6%	4.53
10	Medical Journals	24.6%	6.13	10	Medical Journals	21.0%	6.29
11	Email from Relatives, Friends, and Acquaintances	17.4%	5.03	11	Email from Relatives, Friends, and Acquaintances	18.0%	5.13
12	National/Local Medical Information Services	15.6%	6.04	12	National/Local Medical Information Services	15.0%	6.04
13	Narratives	13.8%	5.27	13	Talking with a Support Group	13.8%	5.36
14	Email from Physician or Physician's Assistant	10.8%	5.65	14	Email from Physician or Physician's Assistant	13.8%	5.86
15	Talking with a Support Group	10.2%	4.74	15	Narratives	13.2%	5.43
16	Films/Movies	9.6%	5.38	16	Educational Programs by HMO or Hospital	9.6%	5.76
17	Educational Programs by HMO or Hospital	9.0%	5.50	17	Email from Nurse or Other Health Professionals	9.0%	6.29
18	Audio/Video Tapes	7.8%	5.25	18	Films/Movies	7.2%	5.08
19	Email from Nurse or Other Health Professionals	7.2%	6.40	19	Email or Chat-room with Other Patients	7.2%	5.30
20	Message Board	7.2%	5.00	20	Message Board	6.6%	5.25
21	Telephone/Helpline	6.6%	5.91	21	Telephone/Helpline	6.0%	6.20
22	Email or Chat-room with a Support Group	4.2%	4.71	22	Email or Chat-room with a Support Group	6.0%	5.11
23	Email or Chat-room with Other Patients	2.4%	4.50	23	Audio/Video Tapes	4.8%	4.89

To test the hypothesis, we divided all the 23 sources into 6 types: human sources, printed media, networked sources, broadcast media, organization sources, and other sources (See Table 31). For both patients and companions, if one went to or will go to at least one of the sources included by a source type, he/she will be counted as using that source type.

Table 31: Sources Included in Each Source Type

Source Type	Sources Included
Human sources	Talking with Physician or Physician's Assistant
	Talking with Nurse or Other Health Professionals
	Talking with a Support Group
	Talking with Other Patients
	Talking with Relatives, Friends, and Acquaintances
	Narratives
Printed media	Medical Leaflets or Pamphlets
	Books
	Medical Journals
	Newspapers / Magazines
Networked sources	Email from Physician or Physician's Assistant
	Email from Nurse or Other Health Professionals
	Email or Chat-room with a Support Group
	Email or Chat-room with Other Patients
	Email from Relatives, Friends, and Acquaintances
	Internet or Medical Websites
	Telephone or Helpline
Other sources	Message Board
	Audio/Video Tapes
Broadcast media	TV/Radio
	Films/Movies
Organizational sources	Educational Programs by HMO or Hospital
	National/Local Medical Information Services

With all these sources regrouped, Frequency Table was run to show the percentages of using these 6 source types. Table 32 lists the percentages of responders who use various source types for general population and cancer patients and companions. The table also ranks the source types by percentage from high to low according to the general population. It shows that either for current or in the future, cancer patients and companions are quite similar with the general population in using different types of sources: they ranked sources including human, printed media, and networked sources as the top 3 most frequently used sources; they ranked broadcast media and organizational sources as less frequently used sources. For other sources, the general population ranked it as the fourth but cancer patients and companions ranked it as the last. Other than that, the information source horizon of cancer patients and companions seems to be accordant with the one of the general population.

Table 32: Comparison of Use of Sources (General Population vs. Cancer Reponders)

Source Type	% of Responders Who Used or Will Use This Source Type							Richness
	General Population	Cancer Patients and Companions						
		Overall (N=424)		Patient (N=257)		Companion (N=167)		
		Current	Future	Current	Future	Current	Future	
Human sources	76.2%	99.3%	86.6%	99.2%	86.8%	99.4%	86.2%	High
Printed media	66.2%	75.5%	60.8%	74.7%	61.1%	76.6%	60.5%	Low - Medium
Networked sources	54.9%	53.3%	46.7%	47.1%	39.7%	62.9%	57.5%	Low - Medium
Other sources	36.6%	***12.3%***	***9.2%***	***12.8%***	***9.3%***	***11.4%***	***9.0%***	
Broadcast media	34.0%	30.0%	23.3%	29.6%	22.6%	30.5%	24.6%	Medium - High
Organizational sources	31.7%	19.6%	18.4%	19.1%	17.5%	20.4%	19.8%	High

To further test whether there are significant differences either between patient and companion or between current and future, Z-test was run for the comparison between "yes" proportions and Paired Samples T-test was run for the comparison within each case. Besides, for variables whose sample size is less than 20, *P*-value was received from *t*-score instead of *z*-score.

Table 33-35 list details about the use of sources and also evaluations of information qualities for these sources by overall, patient, and companion respectively. Here in hypothesis 3 testing, we only discuss the source use, but leave the discussions about information quality evaluations for hypothesis 5 testing.

Table 33 lists the use of sources by overall (both patients and companions). It shows that, for most of traditional sources listed, the percentage of being cited overall as a future source significantly descends from being cited as a current source. These sources include: talking with physician or physician's assistant (*P* = .000), talking with nurse or other health professionals (*P* = .000), talking with other patients (*P* = .003), talking with relatives, friends, and acquaintances (*P* = .000), medical leaflets or pamphlets (*P* = .000), books (*P* = .001), TV/radio (*P* = .033), newspapers/magazines (*P* = .003), audio/video tapes (*P* = .042), and films/movies (*P* = .038). While for those newer sources, it depends. For email, the percentage of it being cited as a future source ascends in general from being cited as a current source. However, the use of the Internet or medical websites seems to decline in the future (*P* = .031).

Table 34 lists the use of sources by patients only. It also shows that, for most of traditional sources listed, the percentage of being cited by patients as a future source significantly descends from being cited as a current source, which agrees with the overall. These sources include: talking with physician or physician's assistant (*P* = .000), talking with nurse or other health professionals (*P* = .000), talking with other patients (*P* = .026), talking with relatives, friends, and acquaintances (*P* = .000), medical leaflets or pamphlets (*P* = .004), books (*P* = .021), newspapers/magazines (*P* = .020). However, unlike the overall, patients seem to reduce the use of those newer sources (such as emails and the Internet) in the future.

Table 35 lists the use of sources by companions only. It agrees with the previous two tables that, for most of traditional sources listed, the percentage of being cited as a future source significantly descends from being cited as a current source. These sources include: talking with physician or physician's assistant (*P* = .000), talking with nurse or other health professionals (*P* = .001), talking with other patients (*P* = .029), talking with relatives, friends, and acquaintances (*P* = .000), medical leaflets or pamphlets (*P* = .003), books (*P* = .006), newspapers/magazines (*P* = .030). For those newer sources, companions seem to agree with patients in reducing the use of the

Internet. However, companions seem to increase the use of emails in the future, especially emails from other patients (*P* = .020).

Table 33: Overall Use and Evaluation of Medical Information Sources

	Current				Future				Current vs. Future			
Sources	Yes %	Quality Level			Yes %	Quality Level				Yes %	Quality Level Differences	
	N = 424	N	Scale	%	N = 424	N	Scale	%		Differences	Z-test	Paired Sample T-test
1 Talking with Physician or Physician's Assistant	97.2%	410	Very Poor = 1	0.2%	84.0%	358	Very Poor = 1	0.0%	N	424		354
			Poor = 2	0.0%			Poor = 2	0.0%	Mean	-13.2%	0.17	0.14
			Below Average = 3	1.0%			Below Average = 3	0.0%	Sig.	***.000***	***.004***	***.000***
			Average = 4	4.9%			Average = 4	3.4%				
			Good = 5	15.1%			Good = 5	12.3%				
			Very Good = 6	28.0%			Very Good = 6	26.5%				
			Excellent = 7	50.7%			Excellent = 7	57.8%				
			Mean 6.22				**Mean 6.39**					
2 Talking with Nurse or Other Health Professionals	83.7%	353	Very Poor = 1	0.0%	69.6%	300	Very Poor = 1	0.0%	N	424		294
			Poor = 2	0.6%			Poor = 2	0.0%	Mean	-14.1%	0.14	0.13
			Below Average = 3	0.8%			Below Average = 3	1.0%	Sig.	***.000***	***.037***	***.000***
			Average = 4	7.1%			Average = 4	6.7%				
			Good = 5	20.1%			Good = 5	14.3%				
			Very Good = 6	31.7%			Very Good = 6	32.0%				
			Excellent = 7	39.7%			Excellent = 7	46.0%				
			Mean 6.01				**Mean 6.15**					
3 Talking with a Support Group	13.9%	63	Very Poor = 1	7.9%	14.4%	60	Very Poor = 1	3.3%	N	424		39
			Poor = 2	3.2%			Poor = 2	1.7%	Mean	0.5%	0.50	0.21
			Below Average = 3	9.5%			Below Average = 3	6.7%	Sig.	.421	***.047***	***.019***
			Average = 4	27.0%			Average = 4	20.0%				
			Good = 5	20.6%			Good = 5	23.3%				
			Very Good = 6	9.5%			Very Good = 6	21.7%				
			Excellent = 7	22.2%			Excellent = 7	23.3%				
			Mean 4.67				**Mean 5.17**					
4 Talking with Other Patients	49.1%	204	Very Poor = 1	1.0%	39.9%	171	Very Poor = 1	0.6%	N	424		157
			Poor = 2	4.9%			Poor = 2	1.8%	Mean	-9.2%	0.19	0.06
			Below Average = 3	6.4%			Below Average = 3	4.7%	Sig.	***.003***	.090	.250
			Average = 4	23.5%			Average = 4	26.3%				
			Good = 5	25.5%			Good = 5	24.0%				
			Very Good = 6	20.1%			Very Good = 6	21.1%				
			Excellent = 7	18.6%			Excellent = 7	21.6%				
			Mean 5.02				**Mean 5.21**					

(Table 33 Continued: Overall Use and Evaluation of Medical Information Sources)

	Current				Future				Current vs. Future			
Sources (Continued)	Yes %	Quality Level			Yes %	Quality Level				Yes %	Quality Level Differences	
	N = 424	N	Scale	%	N = 424	N	Scale	%		Differences	Z-test	Paired Sample T-test
5 Talking with Relatives, Friends, and Acquaintances	66.7%	281	Very Poor = 1	2.8%	47.9%	208	Very Poor = 1	0.0%	N	424		203
			Poor = 2	6.8%			Poor = 2	5.8%	Mean	-18.8%	0.20	0.09
			Below Average = 3	10.3%			Below Average = 3	11.1%	Sig.	***.000***	.082	.053
			Average = 4	20.3%			Average = 4	20.2%				
			Good = 5	25.3%			Good = 5	25.0%				
			Very Good = 6	12.8%			Very Good = 6	12.0%				
			Excellent = 7	21.7%			Excellent = 7	26.0%				
			Mean 4.84				**Mean 5.04**					
6 Email from Physician or Physician's Assistant	9.0%	36	Very Poor = 1	2.8%	9.7%	41	Very Poor = 1	0.0%	N	424		31
			Poor = 2	2.8%			Poor = 2	2.4%	Mean	0.7%	0.35	0.03
			Below Average = 3	2.8%			Below Average = 3	0.0%	Sig.	.363	.123	.787
			Average = 4	11.1%			Average = 4	7.3%				
			Good = 5	11.1%			Good = 5	12.2%				
			Very Good = 6	36.1%			Very Good = 6	39.0%				
			Excellent = 7	33.3%			Excellent = 7	39.0%				
			Mean 5.67				**Mean 6.02**					
7 Email from Nurse or Other Health Professionals	6.6%	24	Very Poor = 1	4.2%	6.8%	26	Very Poor = 1	0.0%	N	424		16
			Poor = 2	0.0%			Poor = 2	0.0%	Mean	0.2%	0.52	0.19
			Below Average = 3	4.2%			Below Average = 3	0.0%	Sig.	.444	.074	.456
			Average = 4	8.3%			Average = 4	7.7%				
			Good = 5	16.7%			Good = 5	7.7%				
			Very Good = 6	29.2%			Very Good = 6	38.5%				
			Excellent = 7	37.5%			Excellent = 7	46.2%				
			Mean 5.71				**Mean 6.23**					
8 Email or Chat-room with a Support Group	4.7%	20	Very Poor = 1	5.0%	5.0%	21	Very Poor = 1	0.0%	N	424		16
			Poor = 2	5.0%			Poor = 2	4.8%	Mean	0.3%	0.58	0.25
			Below Average = 3	10.0%			Below Average = 3	4.8%	Sig.	.436	.125	.216
			Average = 4	25.0%			Average = 4	19.0%				
			Good = 5	15.0%			Good = 5	19.0%				
			Very Good = 6	20.0%			Very Good = 6	23.8%				
			Excellent = 7	20.0%			Excellent = 7	28.6%				
			Mean 4.8				**Mean 5.38**					

(Table 33 Continued: Overall Use and Evaluation of Medical Information Sources)

	Current				Future				Current vs. Future			
Sources (Continued)	Yes %	Quality Level			Yes %	Quality Level				Yes %	Quality Level Differences	
	N = 424	N	Scale	%	N = 424	N	Scale	%		Differences	Z-test	Paired Sample T-test
9 Email or Chat-room with Other Patients	3.1%	13	Very Poor = 1	7.7%	4.2%	16	Very Poor = 1	0.0%	N	424		10
			Poor = 2	0.0%			Poor = 2	0.0%	Mean	1.1%	0.89	0.40
			Below Average = 3	15.4%			Below Average = 3	6.3%	Sig.	.181	.075*	.223
			Average = 4	15.4%			Average = 4	12.5%				
			Good = 5	15.4%			Good = 5	12.5%				
			Very Good = 6	23.1%			Very Good = 6	31.3%				
			Excellent = 7	23.1%			Excellent = 7	37.5%				
			Mean 4.92				**Mean 5.81**					
10 Email from Relatives, Friends, and Acquaintances	16.0%	67	Very Poor = 1	3.0%	14.4%	63	Very Poor = 1	1.6%	N	424		57
			Poor = 2	10.4%			Poor = 2	9.5%	Mean	-1.6%	0.18	0.11
			Below Average = 3	6.0%			Below Average = 3	1.6%	Sig.	.251	.261	***.000***
			Average = 4	20.9%			Average = 4	22.2%				
			Good = 5	23.9%			Good = 5	28.6%				
			Very Good = 6	16.4%			Very Good = 6	15.9%				
			Excellent = 7	19.4%			Excellent = 7	20.6%				
			Mean 4.79				**Mean 4.97**					
11 Educational Programs by HMO or Hospital	9.2%	40	Very Poor = 1	2.5%	10.4%	45	Very Poor = 1	0.0%	N	424		30
			Poor = 2	2.5%			Poor = 2	0.0%	Mean	1.2%	0.56	0.30
			Below Average = 3	15.0%			Below Average = 3	8.9%	Sig.	.281	***.044***	.071
			Average = 4	5.0%			Average = 4	6.7%				
			Good = 5	22.5%			Good = 5	17.8%				
			Very Good = 6	20.0%			Very Good = 6	20.0%				
			Excellent = 7	32.5%			Excellent = 7	46.7%				
			Mean 5.33				**Mean 5.89**					
12 National/Local Medical Information Services	15.1%	63	Very Poor = 1	1.6%	13.2%	57	Very Poor = 1	0.0%	N	424		47
			Poor = 2	1.6%			Poor = 2	0.0%	Mean	-1.9%	0.31	0.21
			Below Average = 3	4.8%			Below Average = 3	1.8%	Sig.	.215	.084	***.049***
			Average = 4	7.9%			Average = 4	8.8%				
			Good = 5	23.8%			Good = 5	21.1%				
			Very Good = 6	25.4%			Very Good = 6	26.3%				
			Excellent = 7	34.9%			Excellent = 7	42.1%				
			Mean 5.67				**Mean 5.98**					

(Table 33 Continued: Overall Use and Evaluation of Medical Information Sources)

	Current				Future				Current vs. Future			
Sources (Continued)	Yes %	Quality Level			Yes %	Quality Level				Yes %	Quality Level Differences	
	N = 424	N	Scale	%	N = 424	N	Scale	%		Differences	Z-test	Paired Sample T-test
13 Medical Leaflets or Pamphlets	54.7%	227	Very Poor = 1	0.9%	41.7%	180	Very Poor = 1	0.0%	N	424		177
			Poor = 2	0.9%			Poor = 2	0.0%	Mean	-13.0%	0.33	0.18
			Below Average = 3	3.5%			Below Average = 3	2.2%	Sig.	***.000***	***.002***	***.000***
			Average = 4	13.7%			Average = 4	11.7%				
			Good = 5	26.0%			Good = 5	18.9%				
			Very Good = 6	30.0%			Very Good = 6	32.8%				
			Excellent = 7	25.0%			Excellent = 7	34.4%				
			Mean 5.53				**Mean 5.86**					
14 Narratives	17.0%	70	Very Poor = 1	2.9%	14.9%	65	Very Poor = 1	0.0%	N	424		54
			Poor = 2	2.9%			Poor = 2	1.5%	Mean	-2.1%	0.27	0.11
			Below Average = 3	7.1%			Below Average = 3	7.7%	Sig.	.201	.132	.224
			Average = 4	18.6%			Average = 4	12.3%				
			Good = 5	18.6%			Good = 5	27.7%				
			Very Good = 6	31.4%			Very Good = 6	26.2%				
			Excellent = 7	18.6%			Excellent = 7	24.6%				
			Mean 5.16				**Mean 5.43**					
15 Message Board	6.6%	29	Very Poor = 1	3.4%	5.9%	26	Very Poor = 1	0.0%	N	424		23
			Poor = 2	3.4%			Poor = 2	0.0%	Mean	-0.7%	0.37	0.30
			Below Average = 3	3.4%			Below Average = 3	3.8%	Sig.	.334	.169	.129
			Average = 4	27.6%			Average = 4	19.2%				
			Good = 5	10.3%			Good = 5	26.9%				
			Very Good = 6	27.6%			Very Good = 6	19.2%				
			Excellent = 7	24.1%			Excellent = 7	30.8%				
			Mean 5.17				**Mean 5.54**					
16 Books	51.7%	215	Very Poor = 1	0.9%	40.8%	175	Very Poor = 1	0.0%	N	424		167
			Poor = 2	2.3%			Poor = 2	1.1%	Mean	-10.9%	0.22	0.11
			Below Average = 3	2.3%			Below Average = 3	2.3%	Sig.	***.001***	***.034***	***.041***
			Average = 4	11.2%			Average = 4	6.9%				
			Good = 5	23.3%			Good = 5	26.3%				
			Very Good = 6	32.6%			Very Good = 6	28.6%				
			Excellent = 7	27.4%			Excellent = 7	34.9%				
			Mean 5.61				**Mean 5.83**					

(Table 33 Continued: Overall Use and Evaluation of Medical Information Sources)

Sources (Continued)	Current				Future				Current vs. Future			
	Yes %	Quality Level			Yes %	Quality Level				Yes %	Quality Level Differences	
	N = 424	N	Scale	%	N = 424	N	Scale	%		Differences	Z-test	Paired Sample T-test
17 Medical Journals	22.4%	94	Very Poor = 1	0.0%	20.3%	88	Very Poor = 1	0.0%	N	424		74
			Poor = 2	0.0%			Poor = 2	0.0%	Mean	-2.1%	0.11	0.07
			Below Average = 3	1.1%			Below Average = 3	1.1%	Sig.	.227	.227	.254
			Average = 4	8.5%			Average = 4	6.8%				
			Good = 5	21.3%			Good = 5	15.9%				
			Very Good = 6	31.9%			Very Good = 6	36.4%				
			Excellent = 7	37.2%			Excellent = 7	39.8%				
			Mean 5.96				**Mean 6.07**					
18 Internet or Medical Websites	46.2%	194	Very Poor = 1	0.5%	39.9%	171	Very Poor = 1	0.0%	N	424		159
			Poor = 2	0.0%			Poor = 2	0.6%	Mean	-6.3%	0.08	0.04
			Below Average = 3	1.0%			Below Average = 3	1.2%	Sig.	***.031***	.251	.329
			Average = 4	13.4%			Average = 4	11.7%				
			Good = 5	27.8%			Good = 5	26.9%				
			Very Good = 6	22.7%			Very Good = 6	21.6%				
			Excellent = 7	34.5%			Excellent = 7	38.0%				
			Mean 5.74				**Mean 5.82**					
19 Telephone or Helpline	6.8%	30	Very Poor = 1	3.3%	5.2%	21	Very Poor = 1	0.0%	N	424		19
			Poor = 2	3.3%			Poor = 2	4.8%	Mean	-1.6%	0.50	0.05
			Below Average = 3	3.3%			Below Average = 3	0.0%	Sig.	.156	.109	.772
			Average = 4	10.0%			Average = 4	9.5%				
			Good = 5	30.0%			Good = 5	14.3%				
			Very Good = 6	20.0%			Very Good = 6	28.6%				
			Excellent = 7	30.0%			Excellent = 7	42.9%				
			Mean 5.4				**Mean 5.9**					
20 TV/Radio	27.1%	114	Very Poor = 1	2.6%	21.7%	96	Very Poor = 1	3.1%	N	424		93
			Poor = 2	7.0%			Poor = 2	7.3%	Mean	-5.4%	0.10	0.12
			Below Average = 3	12.3%			Below Average = 3	9.4%	Sig.	***.033***	.316	.124
			Average = 4	32.5%			Average = 4	29.2%				
			Good = 5	21.9%			Good = 5	25.0%				
			Very Good = 6	11.4%			Very Good = 6	12.5%				
			Excellent = 7	12.3%			Excellent = 7	13.5%				
			Mean 4.47				**Mean 4.57**					

(Table 33 Continued: Overall Use and Evaluation of Medical Information Sources)

	Current				Future				Current vs. Future			
Sources (Continued)	Yes %	Quality Level			Yes %	Quality Level				Yes %	Quality Level Differences	
	N = 424	N	Scale	%	N = 424	N	Scale	%		Differences	Z-test	Paired Sample T-test
21 Newspapers	37.5%	158	Very Poor = 1	2.5%	28.5%	127	Very Poor = 1	1.6%	N	424		121
/Magazines			Poor = 2	1.9%			Poor = 2	1.6%	Mean	-9.0%	0.12	0.09
			Below Average = 3	8.9%			Below Average = 3	6.3%	Sig.	***.003***	.224	***.021***
			Average = 4	25.9%			Average = 4	26.0%				
			Good = 5	30.4%			Good = 5	32.3%				
			Very Good = 6	17.1%			Very Good = 6	18.9%				
			Excellent = 7	13.3%			Excellent = 7	13.4%				
			Mean 4.84				**Mean 4.96**					
22 Audio/Video	8.7%	38	Very Poor = 1	2.6%	5.7%	24	Very Poor = 1	4.2%	N	424		21
Tapes			Poor = 2	2.6%			Poor = 2	0.0%	Mean	-3.0%	-0.12	0.05
			Below Average = 3	2.6%			Below Average = 3	4.2%	Sig.	***.042***	.378	.666
			Average = 4	26.3%			Average = 4	20.8%				
			Good = 5	18.4%			Good = 5	25.0%				
			Very Good = 6	15.8%			Very Good = 6	29.2%				
			Excellent = 7	31.6%			Excellent = 7	16.7%				
			Mean 5.29				**Mean 5.17**					
23 Films/Movies	9.7%	42	Very Poor = 1	2.4%	6.4%	29	Very Poor = 1	3.4%	N	424		26
			Poor = 2	2.4%			Poor = 2	3.4%	Mean	-3.3%	0.05	0.15
			Below Average = 3	11.9%			Below Average = 3	3.4%	Sig.	***.038***	.448	.294
			Average = 4	14.3%			Average = 4	20.7%				
			Good = 5	23.8%			Good = 5	17.2%				
			Very Good = 6	16.7%			Very Good = 6	27.6%				
			Excellent = 7	28.6%			Excellent = 7	24.1%				
			Mean 5.19				**Mean 5.24**					

* *P* value from *t*-score when either one of the two sample sizes is less than 20.

Table 34: Patient's Use and Evaluation of Medical Information Sources

	Current				Future				Current vs. Future			
Patient Sources	Yes %	Quality Level			Yes %	Quality Level				Yes %	Quality Level Differences	
	N = 257	N	Scale	%	N = 257	N	Scale	%		Differences	Z-test	Paired Sample T-test
1 Talking with Physician or Physician's Assistant	98.1%	250	Very Poor = 1	0.0%	85.2%	220	Very Poor = 1	0.0%	N	257		219
			Poor = 2	0.0%			Poor = 2	0.0%	Mean	-12.9%	0.16	0.13
			Below Average = 3	1.2%			Below Average = 3	0.0%	Sig.	***.000***	***.023***	***.002***
			Average = 4	4.8%			Average = 4	3.2%				
			Good = 5	12.4%			Good = 5	10.0%				
			Very Good = 6	26.8%			Very Good = 6	25.0%				
			Excellent = 7	54.8%			Excellent = 7	61.8%				
			Mean 6.29				**Mean 6.45**					
2 Talking with Nurse or Other Health Professionals	83.7%	215	Very Poor = 1	0.0%	69.3%	182	Very Poor = 1	0.0%	N	257		180
			Poor = 2	0.0%			Poor = 2	0.0%	Mean	-14.4%	0.15	0.13
			Below Average = 3	0.5%			Below Average = 3	0.5%	Sig.	***.000***	.056	***.002***
			Average = 4	6.5%			Average = 4	6.6%				
			Good = 5	20.0%			Good = 5	12.1%				
			Very Good = 6	33.0%			Very Good = 6	33.0%				
			Excellent = 7	40.0%			Excellent = 7	47.8%				
			Mean 6.06				**Mean 6.21**					
3 Talking with a Support Group	16.3%	44	Very Poor = 1	6.8%	14.8%	38	Very Poor = 1	2.6%	N	257		28
			Poor = 2	4.5%			Poor = 2	2.6%	Mean	-1.5%	0.41	0.29
			Below Average = 3	9.1%			Below Average = 3	7.9%	Sig.	.312	.134	***.018***
			Average = 4	29.5%			Average = 4	26.3%				
			Good = 5	20.5%			Good = 5	21.1%				
			Very Good = 6	6.8%			Very Good = 6	13.2%				
			Excellent = 7	22.7%			Excellent = 7	26.3%				
			Mean 4.64				**Mean 5.05**					
4 Talking with Other Patients	51.8%	130	Very Poor = 1	0.0%	43.2%	111	Very Poor = 1	0.0%	N	257		105
			Poor = 2	3.8%			Poor = 2	1.8%	Mean	-8.6%	0.11	0.04
			Below Average = 3	5.4%			Below Average = 3	3.6%	Sig.	***.026***	.258	.519
			Average = 4	25.4%			Average = 4	28.8%				
			Good = 5	25.4%			Good = 5	23.4%				
			Very Good = 6	20.0%			Very Good = 6	19.8%				
			Excellent = 7	20.0%			Excellent = 7	22.5%				
			Mean 5.12				**Mean 5.23**					

(Table 34 Continued: Patient's Use and Evaluation of Medical Information Sources)

Patient Sources (Continued)	Current				Future				Current vs. Future			
	Yes %	Quality Level			Yes %	Quality Level				Yes %	Quality Level Differences	
	N = 257	N	Scale	%	N = 257	N	Scale	%		Differences	Z-test	Paired Sample T-test
5 Talking with Relatives, Friends, and Acquaintances	65.8%	166	Very Poor = 1	3.0%	47.5%	124	Very Poor = 1	0.0%	N	257		122
			Poor = 2	7.2%			Poor = 2	6.5%	Mean	-18.3%	0.14	0.07
			Below Average = 3	9.0%			Below Average = 3	9.7%	Sig.	***.000***	.227	.304
			Average = 4	19.3%			Average = 4	21.0%				
			Good = 5	25.3%			Good = 5	27.4%				
			Very Good = 6	14.5%			Very Good = 6	10.5%				
			Excellent = 7	21.7%			Excellent = 7	25.0%				
			Mean 4.87				**Mean 5.01**					
6 Email from Physician or Physician's Assistant	7.8%	19	Very Poor = 1	5.3%	7.0%	19	Very Poor = 1	0.0%	N	257		15
			Poor = 2	2.8%			Poor = 2	0.0%	Mean	-0.8%	0.53	0.07
			Below Average = 3	5.3%			Below Average = 3	0.0%	Sig.	.367	.090*	.774
			Average = 4	5.3%			Average = 4	0.0%				
			Good = 5	15.8%			Good = 5	21.1%				
			Very Good = 6	31.6%			Very Good = 6	36.8%				
			Excellent = 7	36.8%			Excellent = 7	42.1%				
			Mean 5.68				**Mean 6.21**					
7 Email from Nurse or Other Health Professionals	6.2%	14	Very Poor = 1	7.1%	5.4%	12	Very Poor = 1	0.0%	N	257		9
			Poor = 2	0.0%			Poor = 2	0.0%	Mean	-0.8%	0.96	0.44
			Below Average = 3	7.1%			Below Average = 3	0.0%	Sig.	.352	***.028****	.312
			Average = 4	14.3%			Average = 4	8.3%				
			Good = 5	21.4%			Good = 5	8.3%				
			Very Good = 6	21.4%			Very Good = 6	41.7%				
			Excellent = 7	28.6%			Excellent = 7	41.7%				
			Mean 5.21				**Mean 6.17**					
8 Email or Chat-room with a Support Group	5.1%	13	Very Poor = 1	7.7%	4.3%	12	Very Poor = 1	0.0%	N	257		11
			Poor = 2	7.7%			Poor = 2	8.3%	Mean	-0.8%	0.73	0.36
			Below Average = 3	7.7%			Below Average = 3	0.0%	Sig.	.337	.150*	.221
			Average = 4	23.1%			Average = 4	16.7%				
			Good = 5	7.7%			Good = 5	16.7%				
			Very Good = 6	15.4%			Very Good = 6	16.7%				
			Excellent = 7	30.8%			Excellent = 7	41.7%				
			Mean 4.85				**Mean 5.58**					

(Table 34 Continued: Patient's Use and Evaluation of Medical Information Sources)

Patient Sources (Continued)	Current				Future				Current vs. Future			
	Yes %	Quality Level			Yes %	Quality Level				Yes %	Quality Level Differences	
	N = 257	N	Scale	%	N = 257	N	Scale	%		Differences	Z-test	Paired Sample T-test
9 Email or	3.5%	9	Very Poor = 1	11.1%	2.3%	6	Very Poor = 1	0.0%	N	257		6
Chat-room			Poor = 2	0.0%			Poor = 2	0.0%	Mean	-1.2%	1.56	0.67
with Other			Below Average = 3	11.1%			Below Average = 3	0.0%	Sig.	.215	.050*	.235
Patients			Average = 4	11.1%			Average = 4	0.0%				
			Good = 5	11.1%			Good = 5	0.0%				
			Very Good = 6	22.2%			Very Good = 6	33.3%				
			Excellent = 7	33.3%			Excellent = 7	66.7%				
			Mean 5.11				**Mean 6.67**					
10 Email from	15.2%	38	Very Poor = 1	5.3%	12.1%	32	Very Poor = 1	3.1%	N	257		31
Relatives,			Poor = 2	13.2%			Poor = 2	12.5%	Mean	-3.1%	0.20	0.23
Friends, and			Below Average = 3	7.9%			Below Average = 3	3.1%	Sig.	.152	.316	.147
Acquaintances			Average = 4	15.8%			Average = 4	12.5%				
			Good = 5	23.7%			Good = 5	34.4%				
			Very Good = 6	15.8%			Very Good = 6	18.8%				
			Excellent = 7	18.4%			Excellent = 7	15.6%				
			Mean 4.61				**Mean 4.81**					
11 Educational	9.3%	26	Very Poor = 1	3.8%	10.9%	28	Very Poor = 1	0.0%	N	257		19
Programs			Poor = 2	0.0%			Poor = 2	0.0%	Mean	1.6%	0.73	0.37
by HMO or			Below Average = 3	15.4%			Below Average = 3	7.1%	Sig.	.278	***.034***	.149
Hospital			Average = 4	7.7%			Average = 4	7.1%				
			Good = 5	23.1%			Good = 5	17.9%				
			Very Good = 6	23.1%			Very Good = 6	17.9%				
			Excellent = 7	26.9%			Excellent = 7	50.0%				
			Mean 5.23				**Mean 5.96**					
12 National/Local	14.8%	36	Very Poor = 1	2.8%	12.1%	32	Very Poor = 1	0.0%	N	257		27
Medical			Poor = 2	0.0%			Poor = 2	0.0%	Mean	-2.7%	0.55	0.26
Information			Below Average = 3	8.3%			Below Average = 3	0.0%	Sig.	.181	***.039***	.148
Services			Average = 4	13.9%			Average = 4	12.5%				
			Good = 5	22.2%			Good = 5	21.9%				
			Very Good = 6	25.0%			Very Good = 6	25.0%				
			Excellent = 7	27.8%			Excellent = 7	40.6%				
			Mean 5.39				**Mean 5.94**					

(Table 34 Continued: Patient's Use and Evaluation of Medical Information Sources)

Patient Sources (Continued)	Current				Future				Current vs. Future			
	Yes %	Quality Level			Yes %	Quality Level				Yes %	Quality Level Differences	
	N = 257	N	Scale	%	N = 257	N	Scale	%		Differences	Z-test	Paired Sample T-test
13 Medical Leaflets or Pamphlets	50.2%	126	Very Poor = 1	1.6%	38.5%	101	Very Poor = 1	0.0%	N	257		99
			Poor = 2	0.0%			Poor = 2	0.0%	Mean	-11.7%	0.39	0.20
			Below Average = 3	3.2%			Below Average = 3	1.0%	Sig.	***.004***	***.005***	***.007***
			Average = 4	11.9%			Average = 4	9.9%				
			Good = 5	25.4%			Good = 5	17.8%				
			Very Good = 6	32.5%			Very Good = 6	32.7%				
			Excellent = 7	25.4%			Excellent = 7	38.6%				
			Mean 5.59				**Mean 5.98**					
14 Narratives	19.1%	48	Very Poor = 1	4.2%	16.0%	42	Very Poor = 1	0.0%	N	257		36
			Poor = 2	2.1%			Poor = 2	2.4%	Mean	-3.1%	0.33	0.17
			Below Average = 3	8.3%			Below Average = 3	4.8%	Sig.	.176	.136	.183
			Average = 4	18.8%			Average = 4	14.3%				
			Good = 5	14.6%			Good = 5	28.6%				
			Very Good = 6	35.4%			Very Good = 6	26.2%				
			Excellent = 7	16.7%			Excellent = 7	23.8%				
			Mean 5.1				**Mean 5.43**					
15 Message Board	6.2%	16	Very Poor = 1	6.3%	5.4%	14	Very Poor = 1	0.0%	N	257		12
			Poor = 2	0.0%			Poor = 2	0.0%	Mean	-0.8%	0.48	0.33
			Below Average = 3	6.3%			Below Average = 3	0.0%	Sig.	.352	.150*	.339
			Average = 4	25.0%			Average = 4	21.4%				
			Good = 5	0.0%			Good = 5	21.4%				
			Very Good = 6	31.3%			Very Good = 6	14.3%				
			Excellent = 7	31.3%			Excellent = 7	42.9%				
			Mean 5.31				**Mean 5.79**					
16 Books	49.8%	126	Very Poor = 1	1.6%	40.9%	106	Very Poor = 1	0.0%	N	257		103
			Poor = 2	3.2%			Poor = 2	0.9%	Mean	-8.9%	0.25	0.14
			Below Average = 3	2.4%			Below Average = 3	3.8%	Sig.	***.021***	.064	.104
			Average = 4	11.1%			Average = 4	4.7%				
			Good = 5	21.4%			Good = 5	28.3%				
			Very Good = 6	33.3%			Very Good = 6	28.3%				
			Excellent = 7	27.0%			Excellent = 7	34.0%				
			Mean 5.56				**Mean 5.81**					

(Table 34 Continued: Patient's Use and Evaluation of Medical Information Sources)

Patient Sources (Continued)	Current				Future				Current vs. Future			
	Yes %	Quality Level			Yes %	Quality Level				Yes %	Quality Level Differences	
	N = 257	N	Scale	%	N = 257	N	Scale	%		Differences	Z-test	Paired Sample T-test
17 Medical Journals	21.0%	54	Very Poor = 1	0.0%	19.8%	53	Very Poor = 1	0.0%	N	257		44
			Poor = 2	0.0%			Poor = 2	0.0%	Mean	-1.2%	0.09	0.07
			Below Average = 3	1.9%			Below Average = 3	1.9%	Sig.	.371	.334	.372
			Average = 4	13.0%			Average = 4	9.4%				
			Good = 5	20.4%			Good = 5	17.0%				
			Very Good = 6	29.6%			Very Good = 6	37.7%				
			Excellent = 7	35.2%			Excellent = 7	34.0%				
			Mean 5.83				**Mean 5.92**					
18 Internet or Medical Websites	39.3%	99	Very Poor = 1	1.0%	33.9%	90	Very Poor = 1	0.0%	N	257		82
			Poor = 2	0.0%			Poor = 2	0.0%	Mean	-5.4%	0.10	0.07
			Below Average = 3	1.0%			Below Average = 3	2.2%	Sig.	.100	.278	.276
			Average = 4	13.1%			Average = 4	11.1%				
			Good = 5	31.3%			Good = 5	30.0%				
			Very Good = 6	20.2%			Very Good = 6	20.0%				
			Excellent = 7	33.3%			Excellent = 7	36.7%				
			Mean 5.68				**Mean 5.78**					
19 Telephone or Helpline	7.0%	19	Very Poor = 1	5.3%	4.7%	11	Very Poor = 1	0.0%	N	257		11
			Poor = 2	5.3%			Poor = 2	9.1%	Mean	-2.3%	0.53	0.09
			Below Average = 3	5.3%			Below Average = 3	0.0%	Sig.	.129	.150*	.676
			Average = 4	10.5%			Average = 4	9.1%				
			Good = 5	31.6%			Good = 5	18.2%				
			Very Good = 6	15.8%			Very Good = 6	27.3%				
			Excellent = 7	26.3%			Excellent = 7	36.4%				
			Mean 5.11				**Mean 5.64**					
20 TV/Radio	26.8%	68	Very Poor = 1	4.4%	21.8%	58	Very Poor = 1	5.2%	N	257		55
			Poor = 2	5.9%			Poor = 2	6.9%	Mean	-5.0%	0.16	0.13
			Below Average = 3	14.7%			Below Average = 3	8.6%	Sig.	.090	.291	.226
			Average = 4	30.9%			Average = 4	25.9%				
			Good = 5	19.1%			Good = 5	24.1%				
			Very Good = 6	10.3%			Very Good = 6	13.8%				
			Excellent = 7	14.7%			Excellent = 7	15.5%				
			Mean 4.44				**Mean 4.6**					

(Table 34 Continued: Patient’s Use and Evaluation of Medical Information Sources)

Patient Sources (Continued)	Current				Future				Current vs. Future			
	Yes %	Quality Level			Yes %	Quality Level				Yes %	Quality Level Differences	
	N = 257	N	Scale	%	N = 257	N	Scale	%		Differences	Z-test	Paired Sample T-test
21 Newspapers /Magazines	37.7%	97	Very Poor = 1	4.1%	29.2%	79	Very Poor = 1	2.5%	N	257		76
			Poor = 2	2.1%			Poor = 2	2.5%	Mean	-8.5%	0.13	0.11
			Below Average = 3	10.3%			Below Average = 3	8.9%	Sig.	***.020***	.274	.059
			Average = 4	25.8%			Average = 4	25.3%				
			Good = 5	27.8%			Good = 5	27.8%				
			Very Good = 6	18.6%			Very Good = 6	20.3%				
			Excellent = 7	11.3%			Excellent = 7	12.7%				
			Mean 4.72				**Mean 4.85**					
22 Audio/Video Tapes	9.3%	26	Very Poor = 1	3.8%	6.2%	15	Very Poor = 1	0.0%	N	257		15
			Poor = 2	3.8%			Poor = 2	0.0%	Mean	-3.1%	0.02	0.07
			Below Average = 3	3.8%			Below Average = 3	6.7%	Sig.	.093	>.100*	.670
			Average = 4	23.1%			Average = 4	20.0%				
			Good = 5	11.5%			Good = 5	20.0%				
			Very Good = 6	19.2%			Very Good = 6	40.0%				
			Excellent = 7	34.6%			Excellent = 7	13.3%				
			Mean 5.31				**Mean 5.33**					
23 Films/Movies	9.7%	26	Very Poor = 1	3.8%	5.8%	16	Very Poor = 1	0.0%	N	257		14
			Poor = 2	3.8%			Poor = 2	6.3%	Mean	-3.9%	0.30	0.21
			Below Average = 3	11.5%			Below Average = 3	0.0%	Sig.	.050	>.100*	.426
			Average = 4	11.5%			Average = 4	18.8%				
			Good = 5	23.1%			Good = 5	18.8%				
			Very Good = 6	23.1%			Very Good = 6	37.5%				
			Excellent = 7	23.1%			Excellent = 7	18.8%				
			Mean 5.08				**Mean 5.38**					

* *P* value from *t*-score when either one of the two sample sizes is less than 20.

Table 35: Companion's Use and Evaluation of Medical Information Sources

		Current				Future					Current vs. Future		
	Companion Sources	Yes %	Quality Level			Yes %	Quality Level				Yes %	Quality Level Differences	
		N = 167	N	Scale	%	N = 167	N	Scale	%		Differences	Z-test	Paired Sample T-test
1	Talking with Physician or Physician's Assistant	95.8%	160	Very Poor = 1	0.6%	82.0%	138	Very Poor = 1	0.0%	N	167		135
				Poor = 2	0.0%			Poor = 2	0.0%	Mean	-13.8%	0.18	0.15
				Below Average = 3	0.6%			Below Average = 3	0.0%	Sig.	***.000***	.050	***.002***
				Average = 4	5.0%			Average = 4	3.6%				
				Good = 5	19.4%			Good = 5	15.9%				
				Very Good = 6	30.0%			Very Good = 6	29.0%				
				Excellent = 7	44.4%			Excellent = 7	51.4%				
				Mean 6.1				**Mean 6.28**					
2	Talking with Nurse or Other Health Professionals	83.8%	138	Very Poor = 1	0.0%	70.1%	118	Very Poor = 1	0.0%	N	167		114
				Poor = 2	1.4%			Poor = 2	0.0%	Mean	-13.7%	0.14	0.12
				Below Average = 3	1.4%			Below Average = 3	1.7%	Sig.	***.001***	.149	***.004***
				Average = 4	8.0%			Average = 4	6.8%				
				Good = 5	20.3%			Good = 5	17.8%				
				Very Good = 6	29.7%			Very Good = 6	30.5%				
				Excellent = 7	39.1%			Excellent = 7	43.2%				
				Mean 5.93				**Mean 6.07**					
3	Talking with a Support Group	10.2%	19	Very Poor = 1	10.5%	13.8%	22	Very Poor = 1	4.5%	N	167		11
				Poor = 2	0.0%			Poor = 2	0.0%	Mean	3.6%	0.62	0.00
				Below Average = 3	10.5%			Below Average = 3	4.5%	Sig.	.156	>.100*	**
				Average = 4	21.1%			Average = 4	9.1%				
				Good = 5	21.1%			Good = 5	27.3%				
				Very Good = 6	15.8%			Very Good = 6	36.4%				
				Excellent = 7	21.1%			Excellent = 7	18.2%				
				Mean 4.74				**Mean 5.36**					
4	Talking with Other Patients	44.9%	74	Very Poor = 1	2.7%	34.7%	60	Very Poor = 1	1.7%	N	167		52
				Poor = 2	6.8%			Poor = 2	1.7%	Mean	-10.2%	0.32	0.10
				Below Average = 3	8.1%			Below Average = 3	6.7%	Sig.	***.029***	.106	.302
				Average = 4	20.3%			Average = 4	21.7%				
				Good = 5	25.7%			Good = 5	25.0%				
				Very Good = 6	20.3%			Very Good = 6	23.3%				
				Excellent = 7	16.2%			Excellent = 7	20.0%				
				Mean 4.85				**Mean 5.17**					

(Table 35 Continued: Companion’s Use and Evaluation of Medical Information Sources)

Companion Sources (Continued)	Current				Future				Current vs. Future			
	Yes %	Quality Level			Yes %	Quality Level				Yes %	Quality Level Differences	
	N = 167	N	Scale	%	N = 167	N	Scale	%		Differences	Z-test	Paired Sample T-test
5 Talking with Relatives, Friends, and Acquaintances	68.3%	115	Very Poor = 1	2.6%	48.5%	84	Very Poor = 1	0.0%	N	167		81
			Poor = 2	6.1%			Poor = 2	4.8%	Mean	-19.8%	0.31	0.14
			Below Average = 3	12.2%			Below Average = 3	13.1%	Sig.	***.000***	.085	.070
			Average = 4	21.7%			Average = 4	19.0%				
			Good = 5	25.2%			Good = 5	21.4%				
			Very Good = 6	10.4%			Very Good = 6	14.3%				
			Excellent = 7	21.7%			Excellent = 7	27.4%				
			Mean 4.79				**Mean 5.1**					
6 Email from Physician or Physician's Assistant	10.8%	17	Very Poor = 1	0.0%	13.8%	22	Very Poor = 1	0.0%	N	167		16
			Poor = 2	5.9%			Poor = 2	4.5%	Mean	3.0%	0.21	0.00
			Below Average = 3	0.0%			Below Average = 3	0.0%	Sig.	.203	>.100*	1.000
			Average = 4	17.6%			Average = 4	13.6%				
			Good = 5	5.9%			Good = 5	4.5%				
			Very Good = 6	41.2%			Very Good = 6	40.9%				
			Excellent = 7	29.4%			Excellent = 7	36.4%				
			Mean 5.65				**Mean 5.86**					
7 Email from Nurse or Other Health Professionals	7.2%	10	Very Poor = 1	0.0%	9.0%	14	Very Poor = 1	0.0%	N	167		7
			Poor = 2	0.0%			Poor = 2	0.0%	Mean	1.8%	-0.11	-0.14
			Below Average = 3	0.0%			Below Average = 3	0.0%	Sig.	.274	>.100*	.356
			Average = 4	0.0%			Average = 4	7.1%				
			Good = 5	10.0%			Good = 5	7.1%				
			Very Good = 6	40.0%			Very Good = 6	35.7%				
			Excellent = 7	50.0%			Excellent = 7	50.0%				
			Mean 6.4				**Mean 6.29**					
8 Email or Chat-room with a Support Group	4.2%	7	Very Poor = 1	0.0%	6.0%	9	Very Poor = 1	0.0%	N	167		5
			Poor = 2	0.0%			Poor = 2	0.0%	Mean	1.8%	0.40	0.00
			Below Average = 3	14.3%			Below Average = 3	11.1%	Sig.	.227	>.101*	**
			Average = 4	28.6%			Average = 4	22.2%				
			Good = 5	28.6%			Good = 5	22.2%				
			Very Good = 6	28.6%			Very Good = 6	33.3%				
			Excellent = 7	0.0%			Excellent = 7	11.1%				
			Mean 4.71				**Mean 5.11**					

(Table 35 Continued: Companion's Use and Evaluation of Medical Information Sources)

Companion Sources (Continued)	Current				Future				Current vs. Future			
	Yes %	Quality Level			Yes %	Quality Level				Yes %	Quality Level Differences	
	N = 167	N	Scale	%	N = 167	N	Scale	%		Differences	Z-test	Paired Sample T-test
9 Email or	2.4%	4	Very Poor = 1	0.0%	7.2%	10	Very Poor = 1	0.0%	N	167		4
Chat-room			Poor = 2	0.0%			Poor = 2	0.0%	Mean	4.8%	0.80	0.00
with Other			Below Average = 3	25.0%			Below Average = 3	10.0%	Sig.	***.020***	>.102*	**
Patients			Average = 4	25.0%			Average = 4	20.0%				
			Good = 5	25.0%			Good = 5	20.0%				
			Very Good = 6	25.0%			Very Good = 6	30.0%				
			Excellent = 7	0.0%			Excellent = 7	20.0%				
			Mean 4.5				**Mean 5.3**					
10 Email from	17.4%	29	Very Poor = 1	0.0%	18.0%	31	Very Poor = 1	0.0%	N	167		26
Relatives,			Poor = 2	6.9%			Poor = 2	6.5%	Mean	0.6%	0.10	0.04
Friends, and			Below Average = 3	3.4%			Below Average = 3	0.0%	Sig.	.444	.394	.327
Acquaintances			Average = 4	27.6%			Average = 4	32.3%				
			Good = 5	24.1%			Good = 5	22.6%				
			Very Good = 6	17.2%			Very Good = 6	12.9%				
			Excellent = 7	20.7%			Excellent = 7	25.8%				
			Mean 5.03				**Mean 5.13**					
11 Educational	9.0%	14	Very Poor = 1	0.0%	9.6%	17	Very Poor = 1	0.0%	N	167		11
Programs			Poor = 2	7.1%			Poor = 2	0.0%	Mean	0.6%	0.26	0.18
by HMO or			Below Average = 3	14.3%			Below Average = 3	11.8%	Sig.	.425	>.100*	.167
Hospital			Average = 4	0.0%			Average = 4	5.9%				
			Good = 5	21.4%			Good = 5	17.6%				
			Very Good = 6	14.3%			Very Good = 6	23.5%				
			Excellent = 7	42.9%			Excellent = 7	41.2%				
			Mean 5.5				**Mean 5.76**					
12 National/Local	15.6%	27	Very Poor = 1	0.0%	15.0%	25	Very Poor = 1	0.0%	N	167		20
Medical			Poor = 2	3.7%			Poor = 2	0.0%	Mean	-0.6%	0.00	0.15
Information			Below Average = 3	0.0%			Below Average = 3	4.0%	Sig.	.440	.500	.083
Services			Average = 4	0.0%			Average = 4	4.0%				
			Good = 5	25.9%			Good = 5	20.0%				
			Very Good = 6	25.9%			Very Good = 6	28.0%				
			Excellent = 7	44.4%			Excellent = 7	44.0%				
			Mean 6.04				**Mean 6.04**					

(Table 35 Continued: Companion's Use and Evaluation of Medical Information Sources)

Companion Sources (Continued)	Current				Future				Current vs. Future			
	Yes %	Quality Level			Yes %	Quality Level				Yes %	Quality Level Differences	
	N = 167	N	Scale	%	N = 167	N	Scale	%		Differences	Z-test	Paired Sample T-test
13 Medical Leaflets or Pamphlets	61.7%	101	Very Poor = 1	0.0%	46.7%	79	Very Poor = 1	0.0%	N	167		78
			Poor = 2	2.0%			Poor = 2	0.0%	Mean	-15.0%	0.23	0.14
			Below Average = 3	4.0%			Below Average = 3	3.8%	Sig.	***.003***	.100	***.015***
			Average = 4	15.8%			Average = 4	13.9%				
			Good = 5	26.7%			Good = 5	20.3%				
			Very Good = 6	26.7%			Very Good = 6	32.9%				
			Excellent = 7	24.8%			Excellent = 7	29.1%				
			Mean 5.47				**Mean 5.7**					
14 Narratives	13.8%	22	Very Poor = 1	0.0%	13.2%	23	Very Poor = 1	0.0%	N	167		18
			Poor = 2	4.5%			Poor = 2	0.0%	Mean	-0.6%	0.16	0.00
			Below Average = 3	4.5%			Below Average = 3	13.0%	Sig.	.436	.348	1.000
			Average = 4	18.2%			Average = 4	8.7%				
			Good = 5	27.3%			Good = 5	26.1%				
			Very Good = 6	22.7%			Very Good = 6	26.1%				
			Excellent = 7	22.7%			Excellent = 7	26.1%				
			Mean 5.27				**Mean 5.43**					
15 Message Board	7.2%	13	Very Poor = 1	0.0%	6.6%	12	Very Poor = 1	0.0%	N	167		11
			Poor = 2	7.7%			Poor = 2	0.0%	Mean	-0.6%	0.25	0.27
			Below Average = 3	0.0%			Below Average = 3	8.3%	Sig.	.413	>.100*	.192
			Average = 4	30.8%			Average = 4	16.7%				
			Good = 5	23.1%			Good = 5	33.3%				
			Very Good = 6	23.1%			Very Good = 6	25.0%				
			Excellent = 7	15.4%			Excellent = 7	16.7%				
			Mean 5				**Mean 5.25**					
16 Books	54.5%	89	Very Poor = 1	0.0%	40.7%	69	Very Poor = 1	0.0%	N	167		64
			Poor = 2	1.1%			Poor = 2	1.4%	Mean	-13.8%	0.18	0.08
			Below Average = 3	2.2%			Below Average = 3	0.0%	Sig.	***.006***	.159	.167
			Average = 4	11.2%			Average = 4	10.1%				
			Good = 5	25.8%			Good = 5	23.2%				
			Very Good = 6	31.5%			Very Good = 6	29.0%				
			Excellent = 7	28.1%			Excellent = 7	36.2%				
			Mean 5.69				**Mean 5.87**					

(Table 35 Continued: Companion's Use and Evaluation of Medical Information Sources)

Companion Sources (Continued)	Current				Future				Current vs. Future			
	Yes %	Quality Level			Yes %	Quality Level				Yes %	Quality Level Differences	
	N = 167	N	Scale	%	N = 167	N	Scale	%		Differences	Z-test	Paired Sample T-test
17 Medical Journals	24.6%	40	Very Poor = 1	0.0%	21.0%	35	Very Poor = 1	0.0%	N	167		30
			Poor = 2	0.0%			Poor = 2	0.0%	Mean	-3.6%	0.16	0.07
			Below Average = 3	0.0%			Below Average = 3	0.0%	Sig.	.218	.206	.489
			Average = 4	2.5%			Average = 4	2.9%				
			Good = 5	22.5%			Good = 5	14.3%				
			Very Good = 6	35.0%			Very Good = 6	34.3%				
			Excellent = 7	40.0%			Excellent = 7	48.6%				
			Mean 6.13				**Mean 6.29**					
18 Internet or Medical Websites	56.9%	95	Very Poor = 1	0.0%	49.1%	81	Very Poor = 1	0.0%	N	167		77
			Poor = 2	0.0%			Poor = 2	1.2%	Mean	-7.8%	0.05	0.01
			Below Average = 3	1.1%			Below Average = 3	0.0%	Sig.	.076	.386	.829
			Average = 4	13.7%			Average = 4	12.3%				
			Good = 5	24.2%			Good = 5	23.5%				
			Very Good = 6	25.3%			Very Good = 6	23.5%				
			Excellent = 7	35.8%			Excellent = 7	39.5%				
			Mean 5.81				**Mean 5.86**					
19 Telephone or Helpline	6.6%	11	Very Poor = 1	0.0%	6.0%	10	Very Poor = 1	0.0%	N	167		8
			Poor = 2	0.0%			Poor = 2	0.0%	Mean	-0.6%	0.29	0.00
			Below Average = 3	0.0%			Below Average = 3	0.0%	Sig.	.409	>.100*	1.000
			Average = 4	9.1%			Average = 4	10.0%				
			Good = 5	27.3%			Good = 5	10.0%				
			Very Good = 6	27.3%			Very Good = 6	30.0%				
			Excellent = 7	36.4%			Excellent = 7	50.0%				
			Mean 5.91				**Mean 6.2**					
20 TV/Radio	27.5%	46	Very Poor = 1	0.0%	21.6%	38	Very Poor = 1	0.0%	N	167		38
			Poor = 2	8.7%			Poor = 2	7.9%	Mean	-5.9%	0.01	0.11
			Below Average = 3	8.7%			Below Average = 3	10.5%	Sig.	.102	.488	.353
			Average = 4	34.8%			Average = 4	34.2%				
			Good = 5	26.1%			Good = 5	26.3%				
			Very Good = 6	13.0%			Very Good = 6	10.5%				
			Excellent = 7	8.7%			Excellent = 7	10.5%				
			Mean 4.52				**Mean 4.53**					

(Table 35 Continued: Companion's Use and Evaluation of Medical Information Sources)

Companion Sources (Continued)	Current				Future				Current vs. Future			
	Yes %	Quality Level			Yes %	Quality Level				Yes %	Quality Level Differences	
	N = 167	N	Scale	%	N = 167	N	Scale	%		Differences	Z-test	Paired Sample T-test
21 Newspapers /Magazines	37.1%	61	Very Poor = 1	0.0%	27.5%	48	Very Poor = 1	0.0%	N	167		45
			Poor = 2	1.6%			Poor = 2	0.0%	Mean	-9.6%	0.12	0.07
			Below Average = 3	6.6%			Below Average = 3	2.1%	Sig.	***.030***	.291	.183
			Average = 4	26.2%			Average = 4	27.1%				
			Good = 5	34.4%			Good = 5	39.6%				
			Very Good = 6	14.8%			Very Good = 6	16.7%				
			Excellent = 7	16.4%			Excellent = 7	14.6%				
			Mean 5.03				**Mean 5.15**					
22 Audio/Video Tapes	7.8%	12	Very Poor = 1	0.0%	4.8%	9	Very Poor = 1	11.1%	N	167		6
			Poor = 2	0.0%			Poor = 2	0.0%	Mean	-3.0%	-0.36	0.00
			Below Average = 3	0.0%			Below Average = 3	0.0%	Sig.	.129	>.100*	**
			Average = 4	33.3%			Average = 4	22.2%				
			Good = 5	33.3%			Good = 5	33.3%				
			Very Good = 6	8.3%			Very Good = 6	11.1%				
			Excellent = 7	25.0%			Excellent = 7	22.2%				
			Mean 5.25				**Mean 4.89**					
23 Films/Movies	9.6%	16	Very Poor = 1	0.0%	7.2%	13	Very Poor = 1	7.7%	N	167		12
			Poor = 2	0.0%			Poor = 2	0.0%	Mean	-2.4%	-0.30	0.08
			Below Average = 3	12.5%			Below Average = 3	7.7%	Sig.	.215	>.100*	.339
			Average = 4	18.8%			Average = 4	23.1%				
			Good = 5	25.0%			Good = 5	15.4%				
			Very Good = 6	6.3%			Very Good = 6	15.4%				
			Excellent = 7	37.5%			Excellent = 7	30.8%				
			Mean 5.38				**Mean 5.08**					

* *P* value from *t*-score when either one of the two sample sizes is less than 20.

** The t cannot be computed because the standard error of the difference is 0.

All the above tables and tests were done regarding either patients or companions as a whole group, but we still do not know whether there are significant differences between a patient and his/her paired companion in using these sources. Therefore, Paired Samples T-test was run within each paired case for both current and future sources (See Table 36). It shows that: 1) for current sources, no big difference was found between paired patients and companions, except that medical leaflets or pamphlets (*P* = .009) and the Internet or medical websites (*P* = .000) were found more frequently used by companions in the past; 2) for future sources, no big difference was found either, except that emails from physician or physician's assistant (*P* = .004) and the Internet or medical websites (*P* = .000) were found more probably used by companions in the future.

Table 36: Paired Samples T-test for Use of Sources (Patient vs. Companion)

Sources	Patient vs. Companion (Paired)	
	Current (N=166) Sig. (2-tailed)	Future (N=166) Sig. (2-tailed)
1 Talking with Physician or Physician's Assistant	.158	.183
2 Talking with Nurse or Other Health Professionals	.725	.702
3 Talking with a Support Group	.836	.733
4 Talking with Other Patients	.134	.102
5 Talking with Relatives, Friends, and Acquaintances	.782	.692
6 Email from Physician or Physician's Assistant	.109	***.004***
7 Email from Nurse or Other Health Professionals	1.000	.253
8 Email or Chat-room with a Support Group	.740	.407
9 Email or Chat-room with Other Patients	.258	.052
10 Email from Relatives, Friends, and Acquaintances	.305	.063
11 Educational Programs by HMO or Hospital	.469	.671
12 National/Local Medical Information Services	.614	.171
13 Medical Leaflets or Pamphlets	***.009***	.090
14 Narratives	.494	.386
15 Message Board	.565	.782
16 Books	.066	.537
17 Medical Journals	.069	.309
18 Internet or Medical Websites	***.000***	***.000***
19 Telephone or Helpline	.809	.619
20 TV/Radio	.309	.529
21 Newspapers /Magazines	.319	.509
22 Audio/Video Tapes	.809	1.000
23 Films/Movies	.671	.440

Table 37-39 lists the rankings of the websites according to the percentage of use or potential use by the overall (See Table 37), patients (See Table 38), and companions (See Table 39). It seems that National Cancer Institute, American Cancer Society, and search engines are always the top 3 most frequently used websites by both patients and companions. Generally speaking, both patients and companions will visit more various websites in the future than in the past.

Table 37: Overall Websites Ranking

Current			Future		
Ranking	**Websites**	**Yes %**	**Ranking**	**Websites**	**Yes %**
1	National Cancer Institute	31.9%	1	National Cancer Institute	31.7%
2	American Cancer Society	30.7%	2	American Cancer Society	31.0%
3	Search Engines	23.6%	3	Search Engines	22.5%
4	WebMD	17.7%	4	CancerTrials	18.2%
5	M.D. Anderson Cancer Center	16.5%	5	National Institute of Health	17.3%
6	National Institute of Health	13.9%	6	WebMD	17.3%
7	CancerTrials	13.5%	7	M.D. Anderson Cancer Center	16.3%
8	Mayo Clinic	13.5%	8	Mayo Clinic	16.1%
9	WebDoctor	10.6%	9	CancerHelp	12.1%
10	Memorial Sloan-Kettering Cancer C.	7.8%	10	American Society of Clinical Oncologist	11.6%
11	American Society of Clinical Oncologist	7.3%	11	WebDoctor	11.6%
12	Medicine Online	6.9%	12	Memorial Sloan-Kettering Cancer C.	10.9%
13	CancerHelp	5.9%	13	Medicine Online	9.2%
14	Oncology Online	4.5%	14	Oncology Online	9.0%
15	PubMed	4.3%	15	Cancer Support Network	8.0%
16	Oncolink	3.8%	16	Oncolink	6.9%
17	Cancer Support Network	3.8%	17	PubMed	6.1%
18	PDQ Database	3.3%	18	Onhealth	6.1%
19	PharmWeb	2.8%	19	PDQ Database	5.7%
20	Onhealth	2.4%	20	PharmWeb	5.0%
21	CenterWatch	0.5%	21	CenterWatch	4.5%

Table 38: Patient Websites Ranking

Current			Future		
Ranking	**Websites**	**Yes %**	**Ranking**	**Websites**	**Yes %**
1	National Cancer Institute	29.7%	1	National Cancer Institute	29.3%
2	American Cancer Society	27.3%	2	American Cancer Society	28.5%
3	Search Engines	18.8%	3	Search Engines	16.4%
4	WebMD	14.8%	4	M.D. Anderson Cancer Center	14.8%
5	M.D. Anderson Cancer Center	14.5%	5	CancerTrials	14.5%
6	Mayo Clinic	12.1%	6	Mayo Clinic	13.3%
7	CancerTrials	11.3%	7	WebMD	13.3%
8	National Institute of Health	10.9%	8	National Institute of Health	12.9%
9	WebDoctor	9.0%	9	CancerHelp	10.5%
10	Memorial Sloan-Kettering Cancer C.	7.4%	10	WebDoctor	9.4%
11	CancerHelp	6.3%	11	American Society of Clinical Oncologist	9.0%
12	Medicine Online	5.9%	12	Memorial Sloan-Kettering Cancer C.	8.2%
13	American Society of Clinical Oncologist	5.5%	13	Oncology Online	7.8%
14	Oncolink	4.3%	14	Medicine Online	5.9%
15	Oncology Online	3.9%	15	Oncolink	5.5%
16	PubMed	3.5%	16	Cancer Support Network	5.1%
17	PDQ Database	2.7%	17	PDQ Database	4.7%
18	Cancer Support Network	2.7%	18	PubMed	4.3%
19	PharmWeb	2.7%	19	CenterWatch	3.1%
20	Onhealth	1.6%	20	Onhealth	2.7%
21	CenterWatch	0.4%	21	PharmWeb	2.7%

Table 39: Companion Websites Ranking

Current			Future		
Ranking	**Websites**	**Yes %**	**Ranking**	**Websites**	**Yes %**
1	American Cancer Society	35.9%	1	National Cancer Institute	35.3%
2	National Cancer Institute	35.3%	2	American Cancer Society	34.7%
3	Search Engines	31.1%	3	Search Engines	31.7%
4	WebMD	22.2%	4	National Institute of Health	24.0%
5	M.D. Anderson Cancer Center	19.8%	5	CancerTrials	24.0%
6	National Institute of Health	18.6%	6	WebMD	23.4%
7	CancerTrials	16.8%	7	Mayo Clinic	20.4%
8	Mayo Clinic	15.6%	8	M.D. Anderson Cancer Center	18.6%
9	WebDoctor	13.2%	9	American Society of Clinical Oncologist	15.6%
10	American Society of Clinical Oncologist	10.2%	10	Memorial Sloan-Kettering Cancer C.	15.0%
11	Memorial Sloan-Kettering Cancer C.	8.4%	11	WebDoctor	15.0%
12	Medicine Online	8.4%	12	CancerHelp	14.4%
13	CancerHelp	5.4%	13	Medicine Online	14.4%
14	Cancer Support Network	5.4%	14	Cancer Support Network	12.6%
15	Oncology Online	5.4%	15	Onhealth	11.4%
16	PubMed	5.4%	16	Oncology Online	10.8%
17	PDQ Database	4.2%	17	Oncolink	9.0%
18	Onhealth	3.6%	18	PubMed	9.0%
19	Oncolink	3.0%	19	PharmWeb	8.4%
20	PharmWeb	3.0%	20	PDQ Database	7.2%
21	CenterWatch	0.6%	21	CenterWatch	6.6%

Hypothesis 4

The fourth hypothesis proposed that there is a significant relation between patients' demographics and their preferences of medical information sources in the past (H4Pa), and demographics can be used as a predictor for patients' preferences of medical information sources in the future (H4Pb). It also proposed that there is a significant relation between companions' demographics and their preferences of medical information sources in the past (H4Ca), and demographics can be used as a predictor for companions' preferences of medical information sources in the future (H4Cb).

To test the hypothesis, One-Way ANOVA was run for both current and future sources by the overall, patients, and companions, with all the demographic information as potential predictors (See Table 41-46). For those variables showing statistic significance, Means Plot was run after each ANOVA table to help see how the factor influences the use of sources (See Figure 13-80).

Table 41-43 list the ANOVA results for current sources:

On the whole (See Table 41 and Figure 13-24), gender, age, race, education, working status, household income, computer ownership, and Internet access availability have certain predicting power for the overall current use of sources; and cancer type, stage, marital status, and having children or not have some but not strong power. It was found that in the past: 1) people with education degrees lower than graduate or professional seemed to talk with physicians or physicians' assistants more often than those with graduate or professional degrees; 2) people with higher household income, who have children, and have Internet accesses seemed to talk with nurses or other health professionals more often than other patients or companions; 3) people who are in breast cancer group, younger than 65, and with higher household income seemed to talk with other patients the most, while those who are in head-neck or "other" cancer group, older than 65, and with lower household income seemed to talk with other patients much less; 4) people who are female and younger than 50 seemed to talk with relatives, friends, and acquaintances more often than who are males and older than 50; 5) people who own computers, have Internet accesses, and with higher household income seemed to use emails more often than other people to communicate with physicians or physicians' assistants; 6) people who are younger than 50, with higher education degrees and higher household income, and who own computers and have Internet accesses seemed to use emails more often than other people to communicate with relatives, friends, and acquaintances; 7) people with graduate or professional degrees, and household income ranged from $50,000 to $74,999 seemed to attend educational programs by HMO or hospitals more often than other people; 8) people who are receiving treatments, and with household income higher than $74,999 seemed to go for national/local medical information services more often than other people; 9) people who are in breast, gynecological, and H.M. cancer groups, and who are female, with higher education degrees, own computers, and have Internet accesses seemed to get information from medical leaflets or pamphlets more often than other people; 10) people who are younger than 50 seemed to get information from narratives more often than other people; 11) people who are female, with higher education degrees, and have Internet accesses seemed to read books for medical information more often than other people, while those who are retired seemed not to read books for medical information; 12) people who are in breast and H.M. cancer groups, and who are female and with higher education degrees seemed to go for medical journals quite a lot, but those who are retired almost did not; 13) people who are younger, with higher education degrees and higher household income, and own computers and Internet accesses seemed to visit Internet or medical websites quite often but other people seldom did; 14) people who are single, divorced, or widowed seemed to use telephone or helpline more often than those who are married or in regular partnership; 15) people who are female, with household income ranged from $25,000 to $49,000, and who do not own computers seemed to go TV/radio for medical information; 16) people who are female and in breast cancer group seemed to read newspapers/magazines for medical information more often than other people; 17) and finally, people who are younger seemed to get information from the movies more often than the older people.

For patients (See Table 42 and Figure 25-34), cancer type, age, race, education, computer ownership, and Internet access availability have certain predicting power for the patient current use of sources; and gender, stage, working status, and household income have some but not strong power. It was found that in the past: 1) patients who own computers and have Internet accesses seemed to talk with nurses or other health professionals more often than those who do not; 2) patients who are in breast and gynecological cancer group, younger than 65, and who own computers and have Internet accesses seemed to talk with other patients more often than other patients; 3) patients who have Internet accesses seemed to use emails more often than other patients to communicate with nurses or other health professionals; 4) the younger the patients, the more often they used emails or chat-rooms with other patients; 5) patients who own computers, have Internet accesses, and with higher household income seemed to use emails more often than other patients to communicate with relatives, friends, and acquaintances; 6) patients with higher education degrees, and those who own computers seemed to attend educational programs by HMO or hospitals more often than other patients; 7) patients who are female, in breast and gynecological cancer groups, receiving treatments, with higher household income, own computers, and have Internet accesses seemed to go for national/local medical information services more often than other patients; 8) patients who are in breast, gynecological, and H.M. cancer groups, and who are female, younger, with higher education degrees, own computers, and have Internet accesses seemed to get information from medical leaflets or pamphlets more often than other patients; 9) patients who are in breast, gynecological, and lung cancer groups seemed to get information from narratives more often than other cancer groups; 10) patients who are female, younger, with higher education degrees, and have Internet accesses seemed to read books for medical information more often than other patients, while those who are retired seemed not to read books for medical information; 11) patients who are female, in breast cancer group, with higher education degrees, and own computers seemed to go for medical journals quite a lot; 12) patients who are younger, in breast cancer group, with higher education degrees and higher household income, non-retired, and own computers and Internet accesses seemed to visit Internet or medical websites quite often but other patients seldom did; 13) patients whose household income ranged from $25,000 to $49,000 seemed to go TV/radio for medical information; 14) patients who are in breast cancer group and in follow-up seemed to read newspapers/magazines for medical information more often than other patients; 15) and finally, patients who are younger seemed to get information from the movies more often than the older patients.

For companions (See Table 43 and Figure 35-44), cancer type of paired patients, gender, age, education, working status, marital status, having children or not, computer ownership, and Internet access availability have some power on the companion current use of sources. It was found that in the past: 1) male companions seemed to talk with physicians or physicians' assistants more often than female companions; 2) companions who are in gynecological, H.M., and lung cancer groups seemed to talk with a support group more often than other cancer groups, and companions in breast and head-neck cancer groups seemed not to talk with a support group at all; 3) companions who are in breast, G.I., and H.M. cancer groups seemed to talk with other patients the most, while those who are in head-neck and "other" cancer group seemed to talk with other patients much less; 4) companions who are female, younger, in full-time sick leave or unemployed seemed to talk with relatives, friends, and acquaintances more often; 5) companions who have higher household income, own computers and have Internet accesses seemed to use emails more often than other companions to communicate with relatives, friends, and acquaintances; 6) companions who are older than 65 and in full-time sick leave seemed to attend educational programs by HMO or hospitals more often than other companions; 7) companions who do not have children seemed to go for medical journals quite a lot; 8) companions who are younger, with higher education degrees, own computers and have Internet accesses seemed to visit Internet or medical websites quite often but other companions seldom did; 9) companions who are single, divorced, or widowed seemed to use telephone or helpline more often than those who are married or in regular partnership; 10) companions who are female seemed to go TV/radio for medical information; 11) companions who own computers seemed to read newspapers/magazines for medical information more often than those who do not; 12) and finally, companions who are younger and do not have children seemed to get information from the movies more often than other companions.

Table 44-46 list the ANOVA results for future sources:

On the whole (See Table 44 and Figure 45-57), gender, age, race, education, working status, household income, computer ownership, and Internet access availability have certain predicting power for the overall future use of sources; and cancer type, stage, marital status, and having children or not have some but not strong power. It was found that in the future: 1) people aged from 50 to 65, with higher education degrees and higher household income, have children, and have Internet accesses seem more probable to talk with nurses or other health professionals; 2) people who are female seem more probable to talk with other patients; 3) people who are female and younger seem more probable to talk with relatives, friends, and acquaintances; 4) people who are still working, own computers, and have Internet accesses seem more probable to use emails to communicate with physicians or physicians' assistants; 5) people who are female, younger, single, divorced, or widowed seem more probable to use emails to communicate with a support group; 6) people who are younger people who are younger, still working, and have no insurance seem more probable to use emails to communicate with other patients; 7) people who are female, younger, with higher education degrees and higher household income, own computers and have Internet accesses seem more probable to use emails to communicate with relatives, friends, and acquaintances; 8) people who are female and with graduate or professional degrees seem more probable to attend educational programs by HMO or hospitals, while people in U.G. cancer group seem not probable to attend; 9) people who are receiving treatments, with higher education degrees and higher household income, own computers and have Internet accesses seem more probable to go for national/local medical information services; 10) people who are female, younger, with higher education degrees, and have Internet accesses seem more probable to get information from medical leaflets or pamphlets; 11) people who are younger seem more probable to get information from narratives; 12) people who are female seem more probable to use message board to get information; 13) people who are female, with higher education degrees, single, and have Internet accesses seem more probable to read books for medical information; 14) people who are in breast and H.M. cancer groups, female, with higher education degrees, and have Internet access seem more probable to go for medical journals; 15) people who are in breast cancer group, younger, with higher education degrees and higher household income, and own computers and Internet accesses seem more probable to visit Internet or medical websites, while those who are retired seem not probable to use Internet in the future; 16) people who are female, with household income ranged from \$25,000 to \$49,000 seem more probable to go TV/radio for medical information; 17) people who are female and in breast cancer group seem more probable to read newspapers/magazines for medical information; 18) people whose household income ranged from \$25,000 to \$49,000 seem more probable to use audio/video tapes for medical information; 19) and finally, people who are younger seem more probable to get information from the movies than old people.

For patients (See Table 45 and Figure 58-68), cancer type, age, race, education, computer ownership, and Internet access availability have certain predicting power for the patient future use of sources; and gender, stage, working status, household income, and having children or not have some but not strong power. It was found that in the future: 1) patients whose education degrees and household income are higher seem more probable to talk with nurses or other health professionals; 2) patients who are younger seem more probable to talk with a support group; 3) patients who are own computers and have Internet accesses seem more probable to talk with other patients, while patients in U.G. and G.I. cancer groups seem not probable to talk with other patients; 4) patients who own computers seem more probable to use emails to communicate with physicians or physicians' assistants; 5) the younger the patients, the more probable they will use emails or chat-rooms with other patients; 6) patients who are in breast cancer group, younger, with higher education degrees and household income, own computers, and have Internet accesses seem more probable to use emails to communicate with relatives, friends, and acquaintances, while patients in U.G. cancer group will probably not; 7) patients with higher education degrees seem more probable to attend educational programs by HMO or hospitals; 8) patients who are receiving treatments, with higher household income, and have Internet accesses seem more probable to go for national/local medical information services; 9) patients who have Internet accesses seem more probable to get information from medical leaflets or pamphlets; 10) patients who are younger, and in breast and gynecological cancer groups seem more probable to get information from narratives; 11) patients who are younger seem more probable to use message board for medical information in the future; 12) patients who are female, in breast cancer group, non-retired, with higher education degrees, and have Internet accesses seem more probable to read books for medical information; 13) patients who own higher education degrees and have Internet accesses seem more probable to go for medical journals; 14) patients who are younger, in breast cancer group, with higher education degrees and higher household income, non-retired, and own computers and Internet accesses seem more probable to visit Internet or medical websites; 15) patients whose household income ranged from $25,000 to $49,000 seem more probable to go TV/radio for medical information; 16) patients who are in breast cancer group and with high education degrees seem more probable to read newspapers/magazines for medical information.

For companions (See Table 46 and Figure 69-80), stage, gender, age, race, education, working status, household income, insurance, marital status, having children or not, computer ownership, and Internet access availability have some power on the companion future use of sources. It was found that in the future: 1) companions who are receiving treatments are more probable to talk with physicians or physicians' assistants; 2) companions who are receiving treatments and have higher household income seem more probable to talk with nurses or other health professionals; 3) companions who are female and receiving treatments seem more probable to talk with other patients; 4) companions who are female, younger, and non-retired seem more probable to talk with relatives, friends, and acquaintances; 4) companions who have medical insurance, single, divorced, or widowed seem more probable to use emails to communicate with a support group; 5) companions who own computers and have Internet accesses seem more probable to use emails to communicate with relatives, friends, and acquaintances; 6) companions who are in full-time sick leave seem more probable to attend educational programs by HMO or hospitals; 7) companions who are receiving treatments and with higher household income seem more probable to go for national/local medical information services; 8) companions who have Internet accesses seem more probable to get information from medical leaflets or pamphlets; 9) companions who are receiving treatments and single seem more probable to get information from narratives; 10) companions who are single seem more probable to use message board to get information; 11) companions who are single seem more probable to read books for medical information; 12) companions who do not have children seem more probable to go for medical journals; 13) companions who are in full-time sick leave, and own computers and Internet accesses seem more probable to visit Internet or medical websites; 14) companions who are female and do not have children seem more probable to go TV/radio for medical information; 15) female companions seem more probable to read newspapers/magazines for medical information; 16) and finally, companions who are female, single, and do not have children seem more probable to get information from the movies.

Table 40: Overall ANOVA for Demographics by Current Sources

Current Sources	Demographics													
	Cancer Type N=424	Diagnosis Date N=424	Stage N=386	Gender N=424	Age N=419	Race N=422	Education N=418	Working Status N=379	Household Income N=373	Insurance N=408	Marital Status N=417	Children N=421	Computer Ownership N=421	Internet Access N=420
1 Talking with Physician or Physician's Assistant	.464	.561	.151	.323	.325	.326	***.028***	.118	.217	.543	.820	.924	.056	.050
2 Talking with Nurse or Other Health Professionals	.354	.090	.207	.547	.079	.099	.169	.539	***.024***	.976	.063	***.009***	.099	***.019***
3 Talking with a Support Group	.115	.668	.383	.569	.185	***.003***	.700	.259	.392	.882	.168	.924	.880	.693
4 Talking with Other Patients	***.011***	.212	.454	.140	***.032***	.296	.179	.320	***.026***	.430	.412	.100	.072	.083
5 Talking with Relatives, Friends, and Acquaintances	.371	.606	.068	***.036***	***.001***	.658	.405	.336	.187	.691	.135	.245	.777	.189
6 Email from Physician or Physician's Assistant	.538	.340	.302	.176	.367	.511	.199	.229	***.022***	.884	.606	.395	***.026***	***.019***
7 Email from Nurse or Other Health Professionals	.665	.151	.208	.619	.572	.351	.454	.785	.122	.340	.626	.501	.135	.110
8 Email or Chat-room with a Support Group	.515	.889	.476	.498	.166	.078	.441	.435	.803	.432	.163	.932	.163	.138
9 Email or Chat-room with Other Patients	.309	.171	.446	.927	.126	***.034***	.726	.484	.618	.525	.156	.422	.518	.470
10 Email from Relatives, Friends, and Acquaintances	.543	.387	.217	.392	***.011***	.726	***.000***	.255	***.000***	.411	.681	.856	***.000***	***.000***
11 Educational Programs by HMO or Hospital	.090	.457	.919	.870	.842	***.009***	***.010***	.169	***.031***	.908	.600	.608	.247	.196
12 National/Local Medical Information Services	.090	.346	***.001***	.148	.524	.056	.114	.749	***.001***	.457	.785	.990	.081	.054
13 Medical Leaflets or Pamphlets	***.036***	.465	.380	***.000***	***.002***	.159	***.001***	***.017***	.211	.639	.702	.388	***.004***	***.000***
14 Narratives	***.015***	.580	.667	.286	***.022***	.135	.271	.270	.104	.530	.959	.447	.498	.134
15 Message Board	.290	.805	.239	.374	.573	***.025***	.893	.513	.853	.812	.078	.834	.775	.760
16 Books	.062	.680	.225	***.004***	.056	***.028***	***.000***	***.000***	.144	.671	.052	.596	.203	***.007***
17 Medical Journals	***.009***	.545	.602	***.001***	.377	***.006***	***.002***	***.038***	.952	.507	.892	.189	.130	.140
18 Internet or Medical Websites	.091	.746	.387	.123	***.000***	.236	***.000***	***.000***	***.007***	.607	.507	.670	***.000***	***.000***
19 Telephone or Helpline	.588	.988	.377	.149	.985	***.000***	.913	.756	.462	.875	**.025**	.443	.275	.622
20 TV/Radio	.454	.244	.135	***.012***	.986	***.023***	.801	.265	***.005***	.332	.074	.413	***.019***	.322
21 Newspapers /Magazines	***.027***	.542	.220	***.037***	.502	***.009***	.062	.846	.082	.599	.169	.625	.477	.928
22 Audio/Video Tapes	.414	.062	.057	.853	.096	***.017***	.688	.128	.719	.932	.251	.206	.360	.521
23 Films/Movies	.307	.735	.784	.145	***.015***	.296	.495	.232	.238	.838	.065	.213	.728	.853

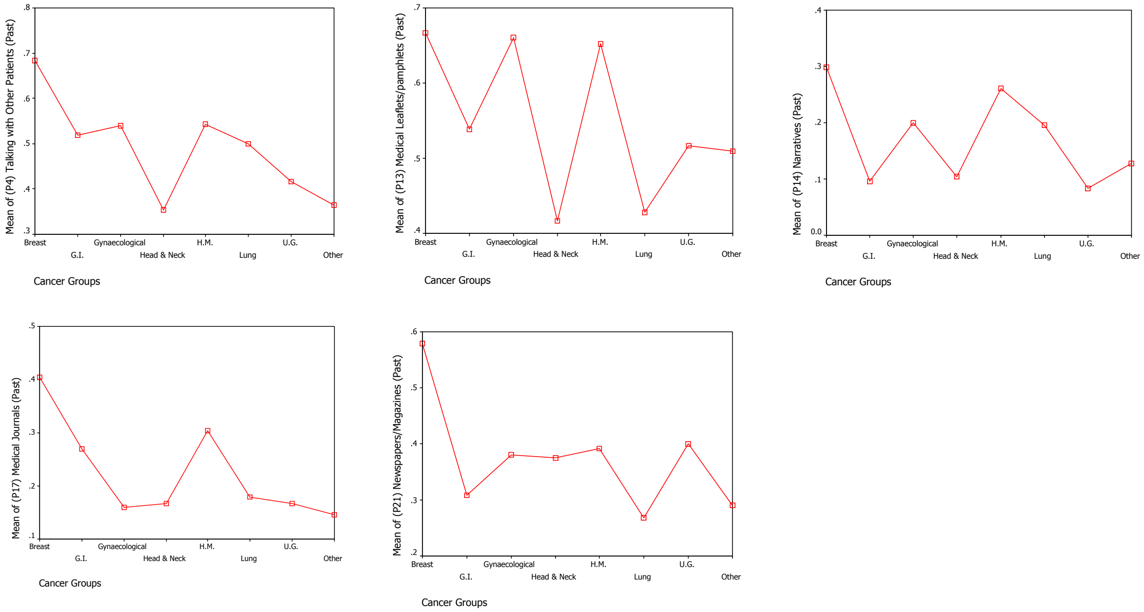


Figure 13: Overall Means Plots for Current Sources Use (1=Yes, 0=No) by Cancer Type (Group)

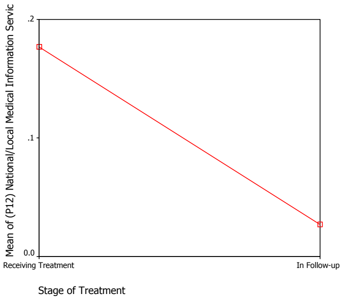


Figure 14: Overall Means Plots for Current Sources Use (1=Yes, 0=No) by Stage

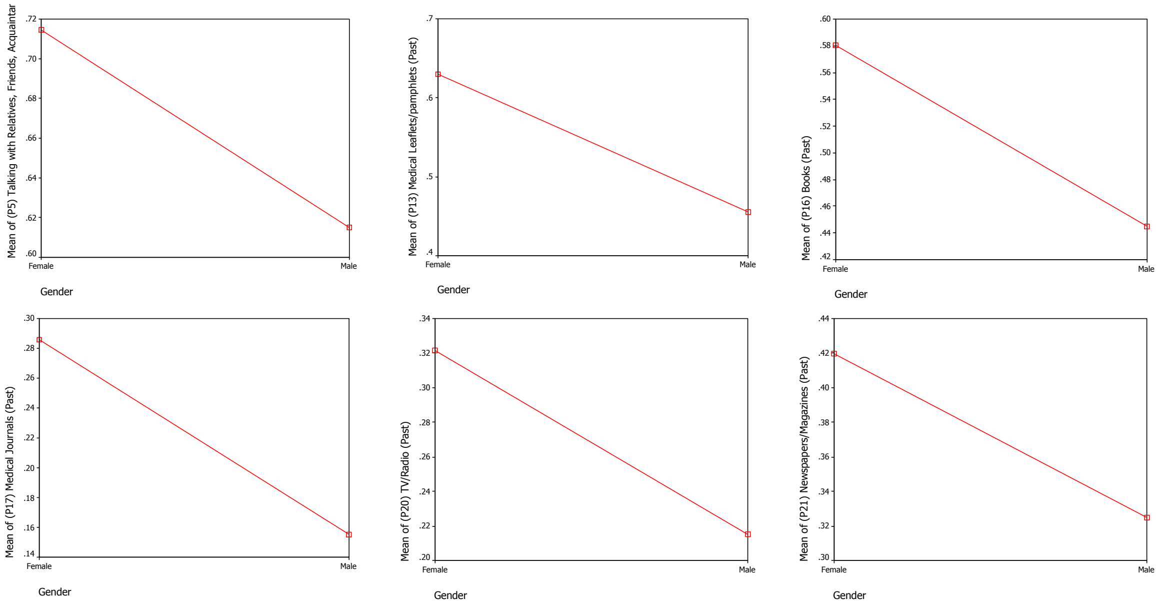


Figure 15: Overall Means Plots for Current Sources Use (1=Yes, 0=No) by Gender

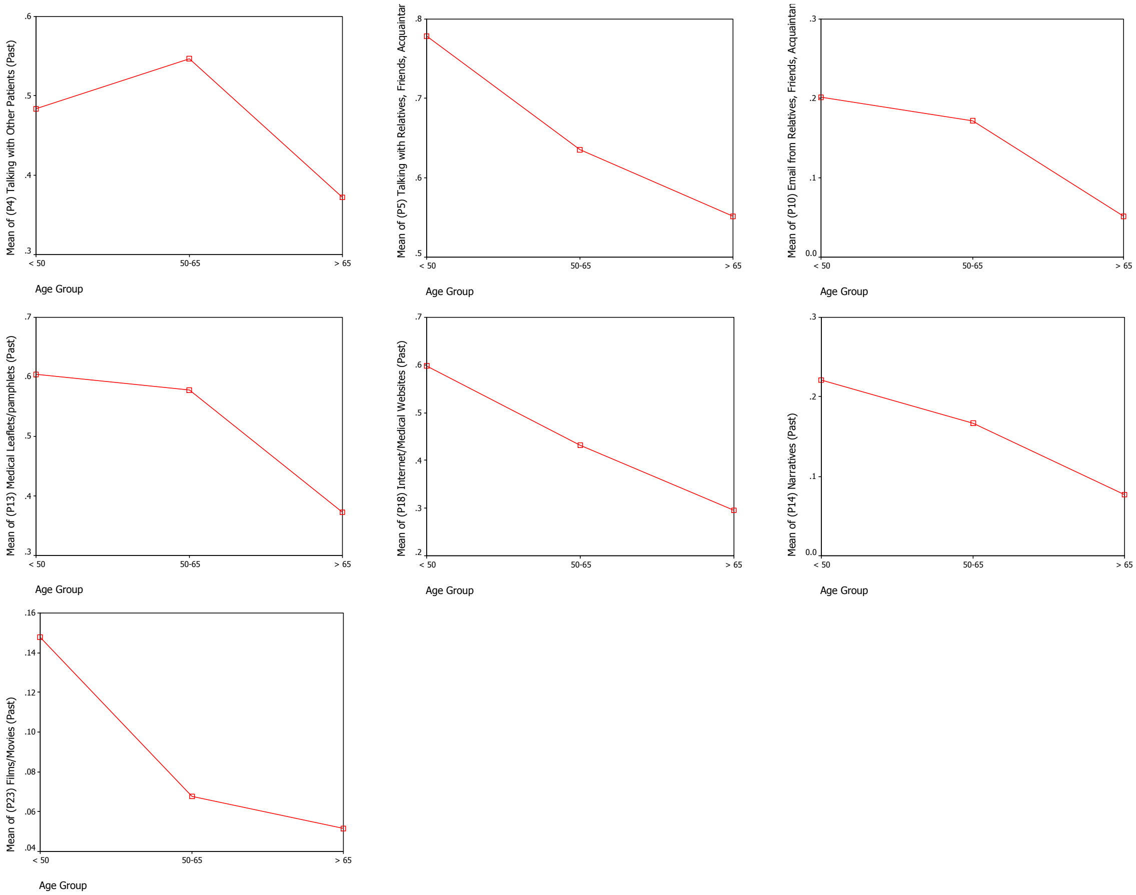


Figure 16: Overall Means Plots for Current Sources Use (1=Yes, 0=No) by Age (Group)

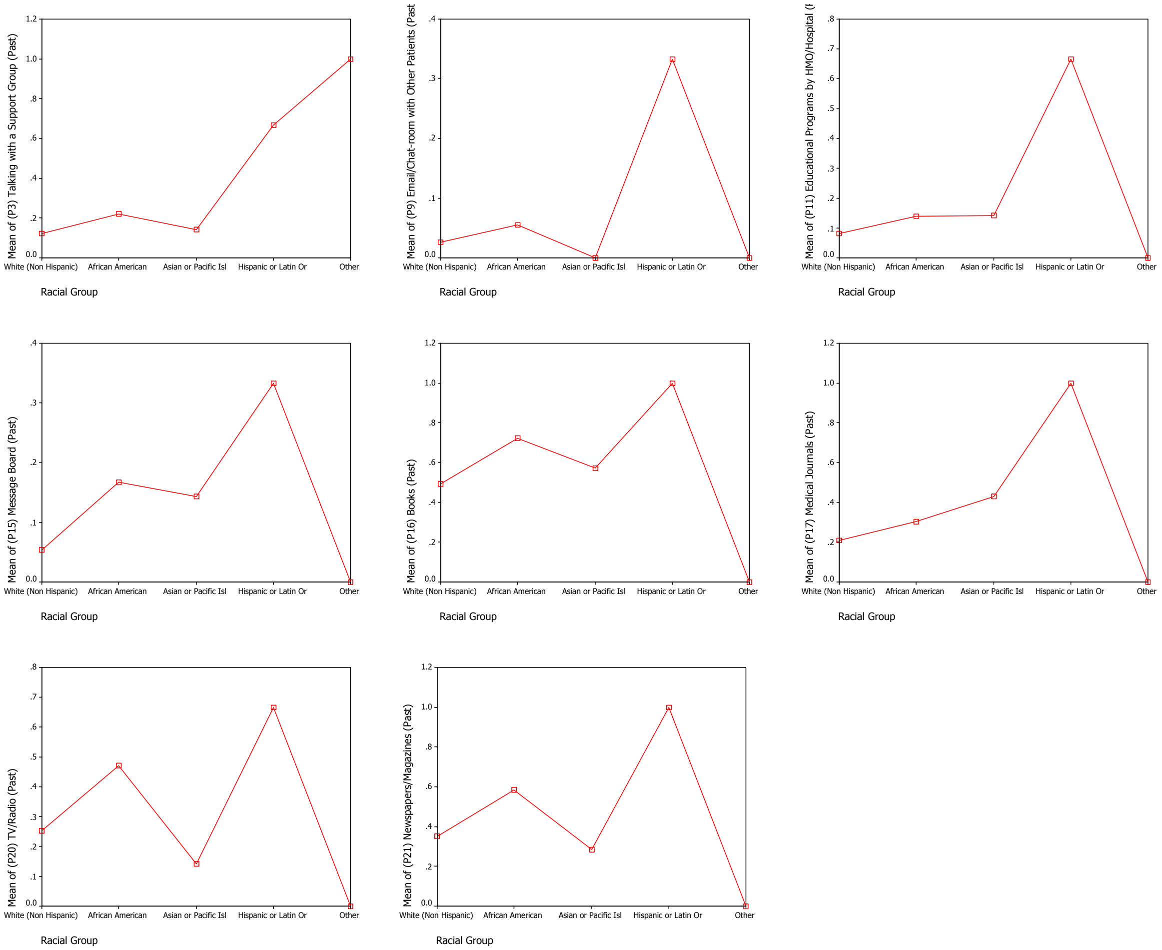


Figure 17: Overall Means Plots for Current Sources Use (1=Yes, 0=No) by Race

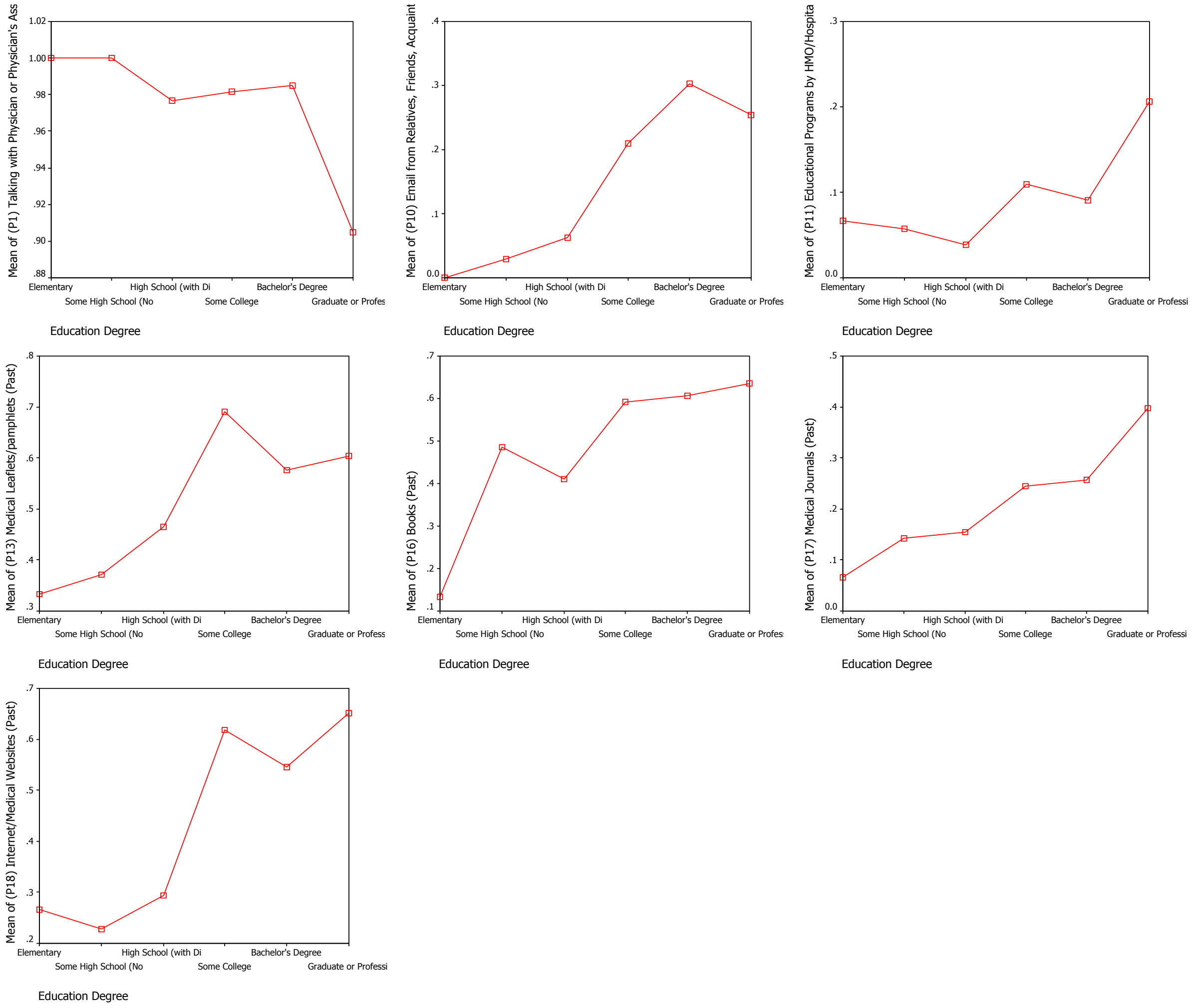


Figure 18: Overall Means Plots for Current Sources Use (1=Yes, 0=No) by Education

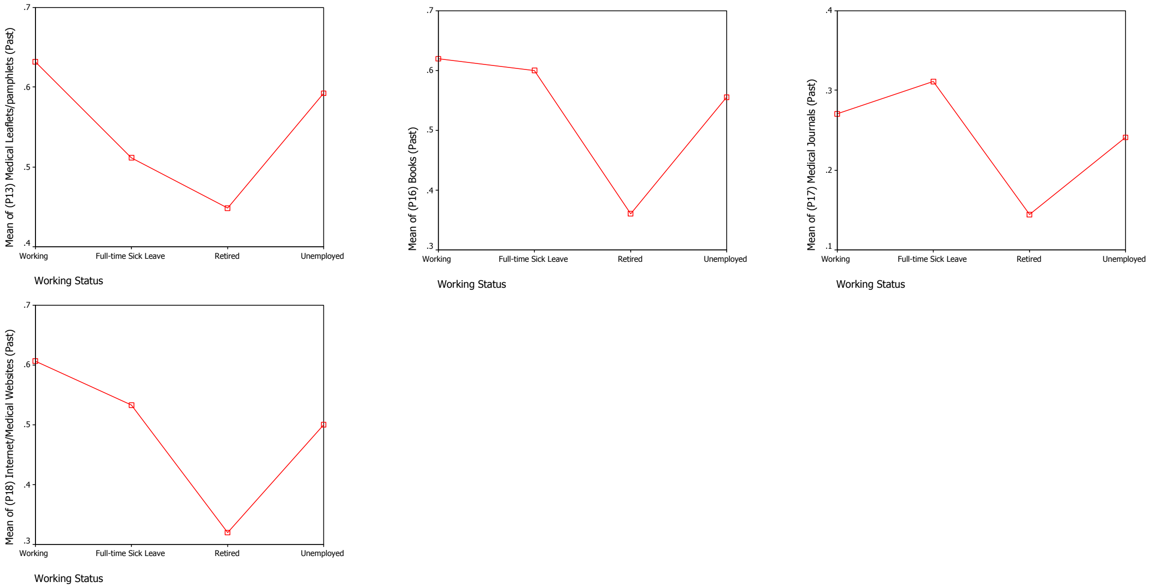


Figure 19: Overall Means Plots for Current Sources Use (1=Yes, 0=No) by Working Status

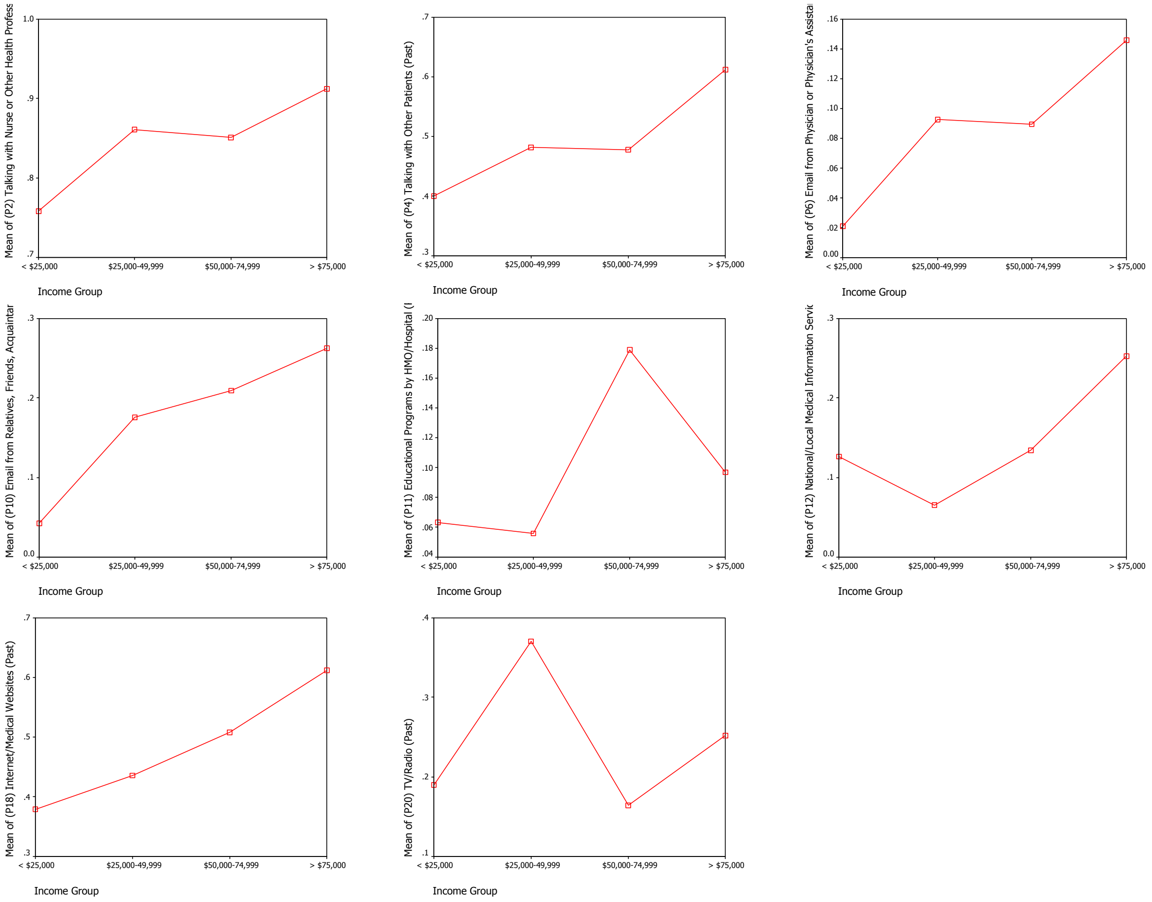


Figure 20: Overall Means Plots for Current Sources Use (1=Yes, 0=No) by Household Income (Group)

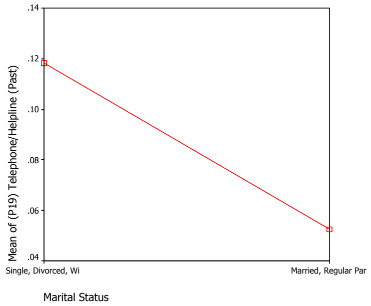


Figure 21: Overall Means Plots for Current Sources Use (1=Yes, 0=No) by Marital Status

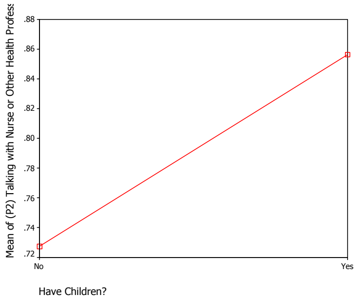


Figure 22: Overall Means Plots for Current Sources Use (1=Yes, 0=No) by Having Children Or Not

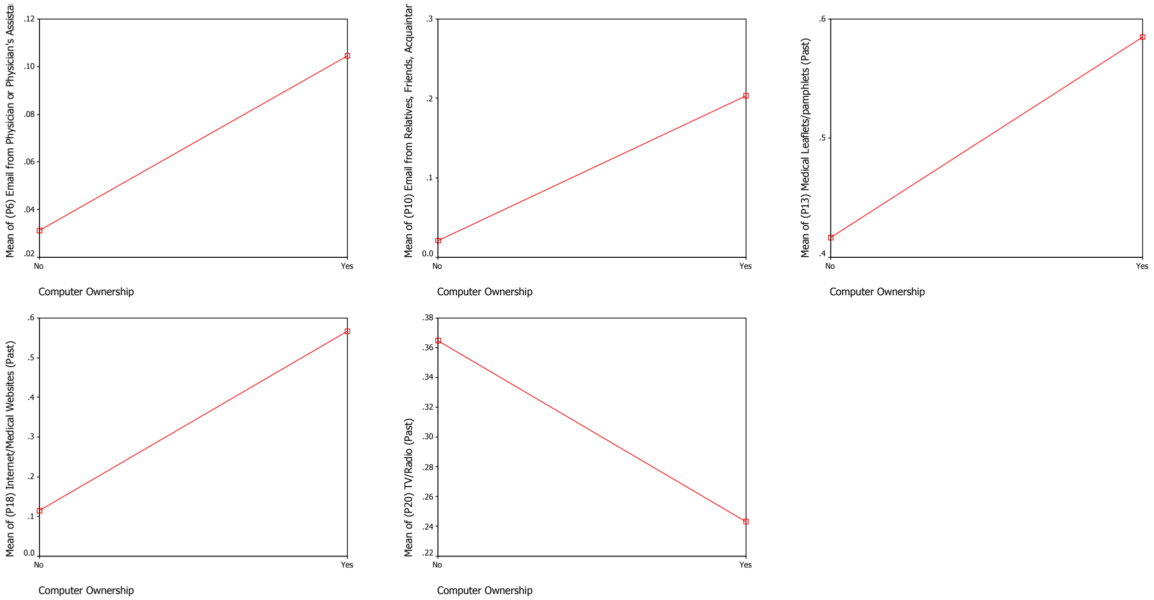


Figure 23: Overall Means Plots for Current Sources Use (1=Yes, 0=No) by Computer Ownership

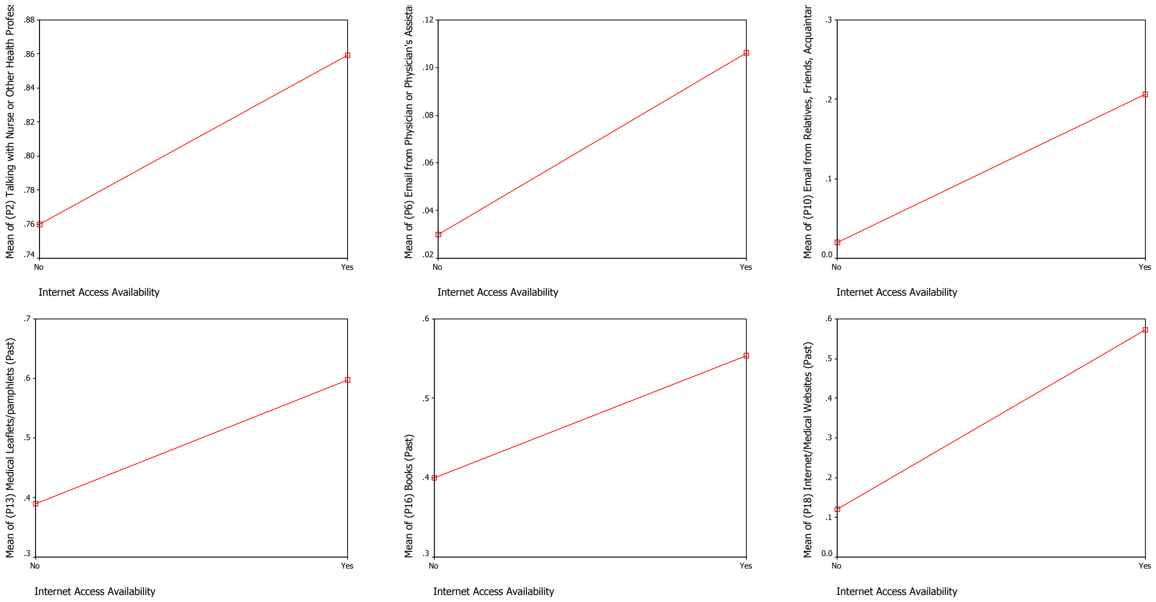


Figure 24: Overall Means Plots for Current Sources Use (1=Yes, 0=No) by Internet Access Availability

Table 41: Patient ANOVA for Demographics by Current Sources

Patient Current Sources	Demographics													
	Cancer Type N=257	Diagnosis Date N=257	Stage N=235	Gender N=257	Age N=253	Race N=256	Education N=253	Working Status N=227	Household Income N=225	Insurance N=247	Marital Status N=252	Children N=255	Computer Ownership N=254	Internet Access N=254
1 Talking with Physician or Physician's Assistant	.550	.316	.303	.249	.225	***.047***	.089	.500	.070	.797	.766	.354	.173	.149
2 Talking with Nurse or Other Health Professionals	.178	.424	.623	.474	.079	.071	.186	.438	.094	.593	.108	.062	***.028***	***.001***
3 Talking with a Support Group	.128	.424	.173	.526	.183	***.002***	.582	.333	.421	.631	.183	.363	.394	.647
4 Talking with Other Patients	***.045***	.467	.989	.107	***.045***	.482	***.022***	.060	.177	.942	.514	.155	***.001***	***.001***
5 Talking with Relatives, Friends, and Acquaintances	.215	.787	.382	.421	.084	.690	.164	.969	.347	.498	.266	.775	.469	.065
6 Email from Physician or Physician's Assistant	.248	.258	.799	.327	.379	.400	.275	.412	.101	.574	.957	.610	.097	.064
7 Email from Nurse or Other Health Professionals	.549	.155	.263	.712	.138	.358	.622	.715	.290	.623	.937	.894	.070	***.049***
8 Email or Chat-room with a Support Group	.808	.401	.920	.538	.130	.079	.585	.829	.764	.665	.286	.927	.112	.081
9 Email or Chat-room with Other Patients	.357	.222	.648	.947	***.027***	***.037***	.607	.865	.378	.714	.600	.769	.282	.227
10 Email from Relatives, Friends, and Acquaintances	.086	.402	.275	.139	.133	.383	***.001***	.525	***.012***	.399	.555	.415	***.000***	***.000***
11 Educational Programs by HMO or Hospital	.231	.970	.980	.645	.266	***.005***	***.014***	.153	.195	.213	.693	.770	***.032***	.060
12 National/Local Medical Information Services	***.016***	.472	***.006***	***.044***	.646	.082	.090	.268	***.010***	.553	.770	.809	***.018***	***.024***
13 Medical Leaflets or Pamphlets	***.012***	.958	.395	***.002***	***.015***	.135	***.038***	.299	.676	.981	.722	.362	***.011***	***.006***
14 Narratives	***.004***	.275	.864	.136	***.023***	.212	.072	.265	.138	.105	.614	.373	.165	.079
15 Message Board	.882	.706	.690	.883	.658	***.003***	.787	.903	.549	.075	.271	.814	.869	.708
16 Books	.053	.578	.292	***.015***	***.027***	***.009***	***.000***	***.000***	.143	.981	.150	.920	.105	***.007***
17 Medical Journals	***.019***	.924	.272	***.010***	.700	***.012***	***.003***	.098	.423	.863	.956	.219	***.031***	.065
18 Internet or Medical Websites	***.045***	.909	.799	.124	***.002***	.127	***.000***	***.001***	.151	.537	.832	.584	***.000***	***.000***
19 Telephone or Helpline	.655	.830	.901	.694	.896	***.000***	.342	.666	.853	.130	.189	.673	.317	.505
20 TV/Radio	.124	.569	.261	.196	.784	***.036***	.848	.100	***.002***	.291	.138	.251	.064	.322
21 Newspapers /Magazines	***.000***	.748	***.027***	.213	.497	***.031***	.059	.715	.327	.121	.203	.481	.432	.400
22 Audio/Video Tapes	.731	.367	.234	.975	.141	***.034***	.453	.386	.582	.541	.131	.409	.289	.415
23 Films/Movies	.333	.834	.885	.873	***.038***	.601	.590	.104	.126	.256	.501	.770	.492	.641

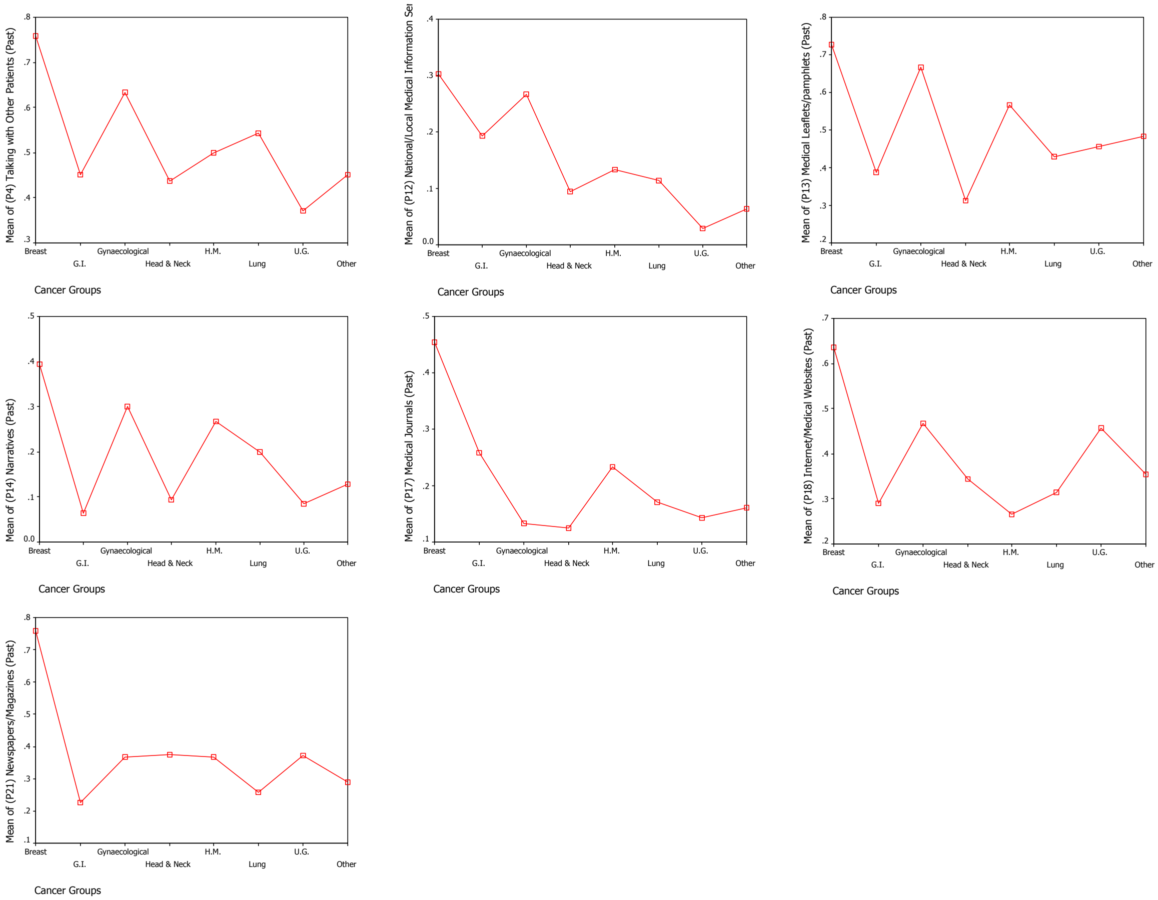


Figure 25: Patient Means Plots for Current Sources Use (1=Yes, 0=No) by Cancer Type (Group)

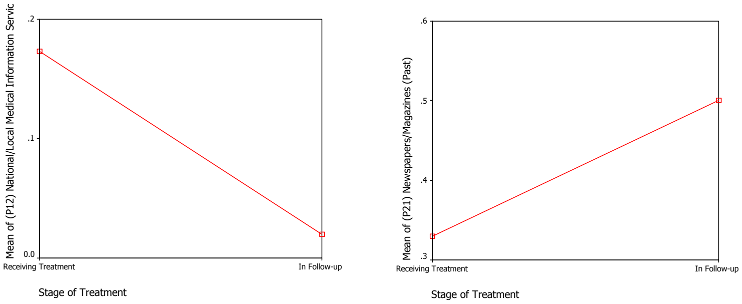


Figure 26: Patient Means Plots for Current Sources Use (1=Yes, 0=No) by Stage

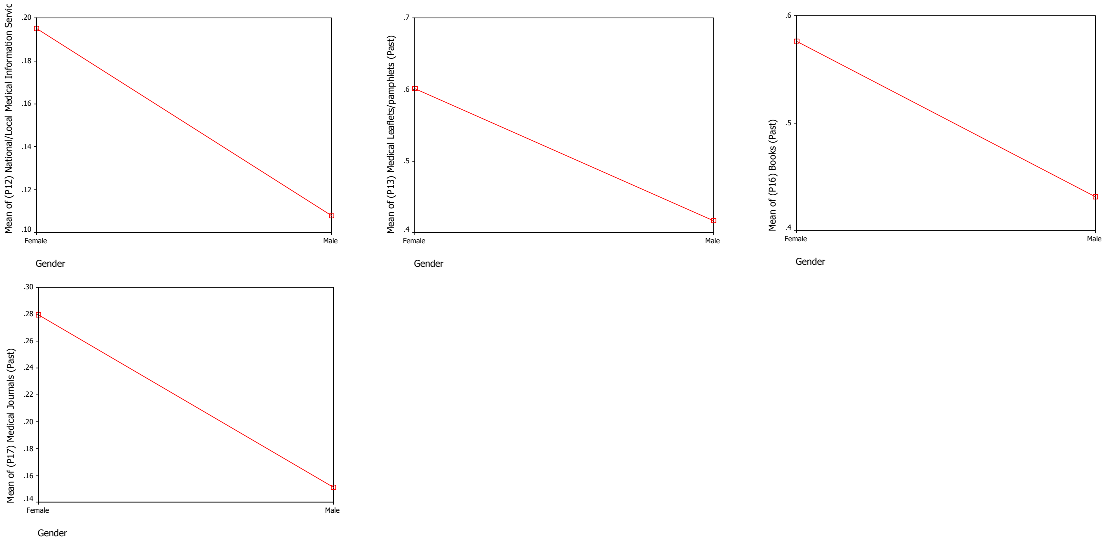


Figure 27: Patient Means Plots for Current Sources Use (1=Yes, 0=No) by Gender

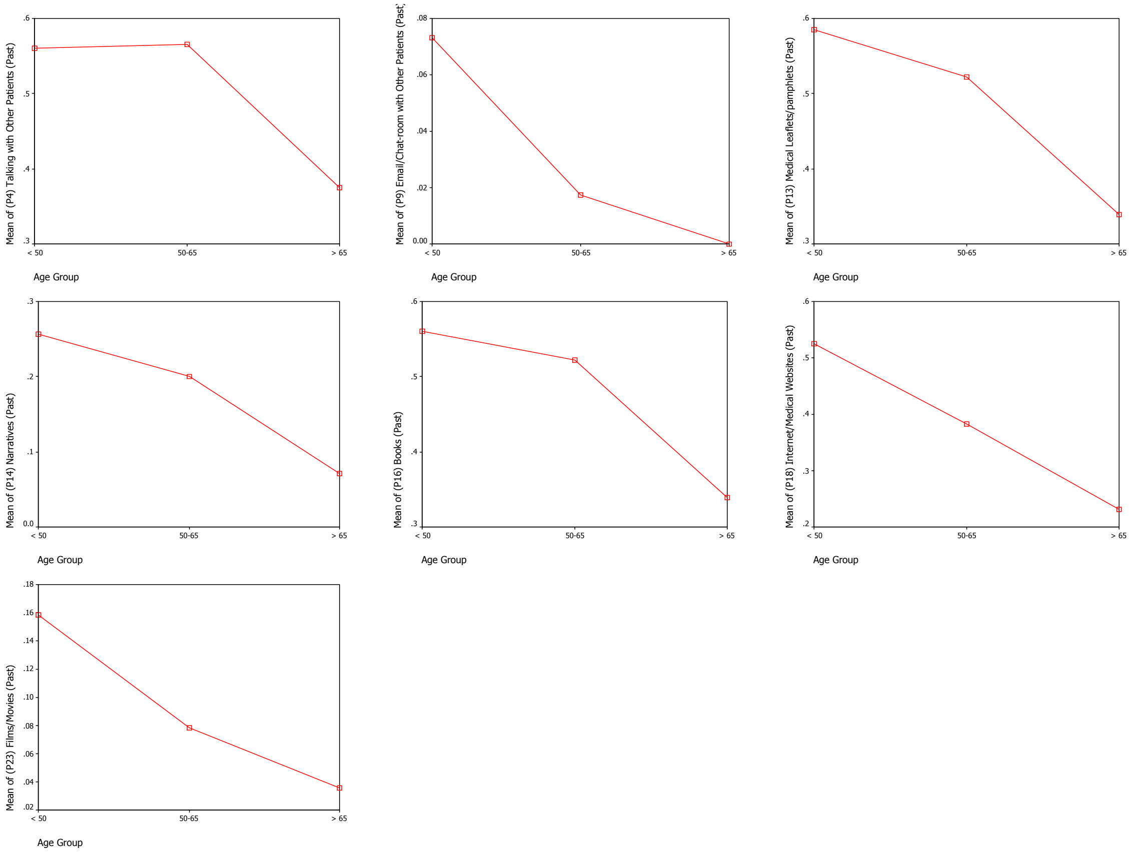


Figure 28: Patient Means Plots for Current Sources Use (1=Yes, 0=No) by Age (Group)

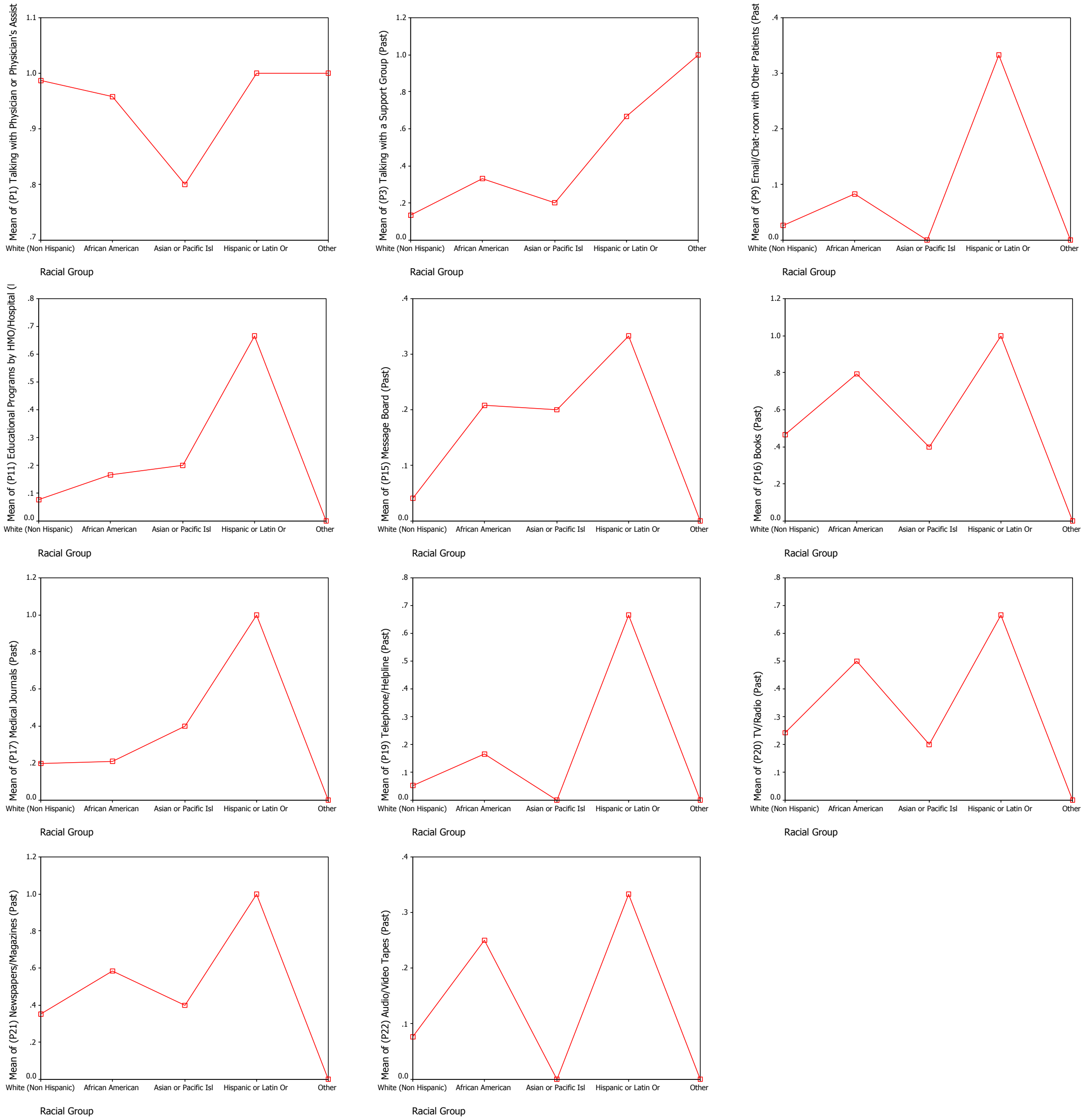


Figure 29: Patient Means Plots for Current Sources Use (1=Yes, 0=No) by Race

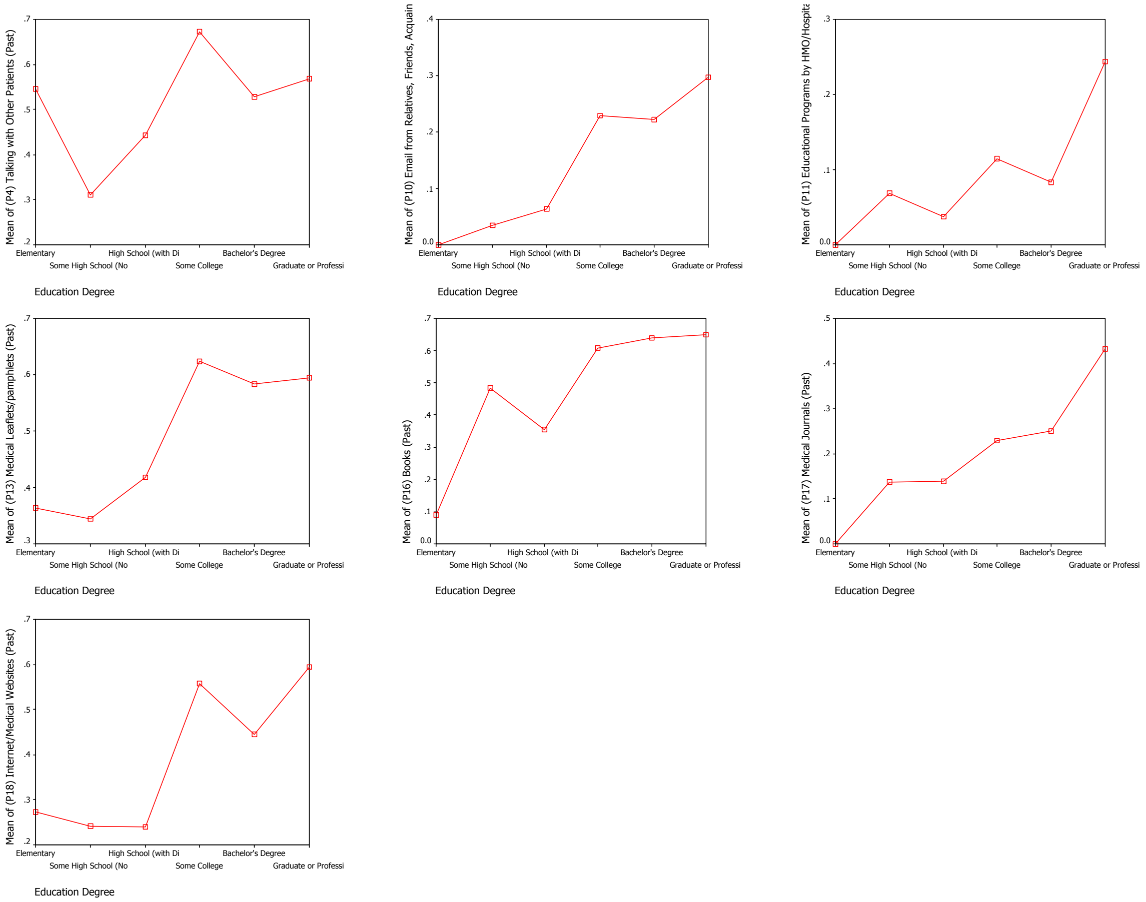


Figure 30: Patient Means Plots for Current Sources Use (1=Yes, 0=No) by Education

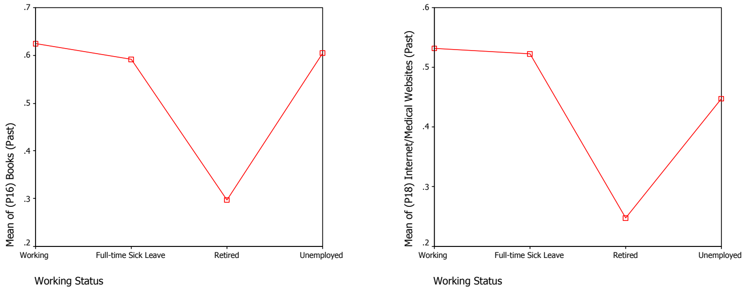


Figure 31: Patient Means Plots for Current Sources Use (1=Yes, 0=No) by Working Status

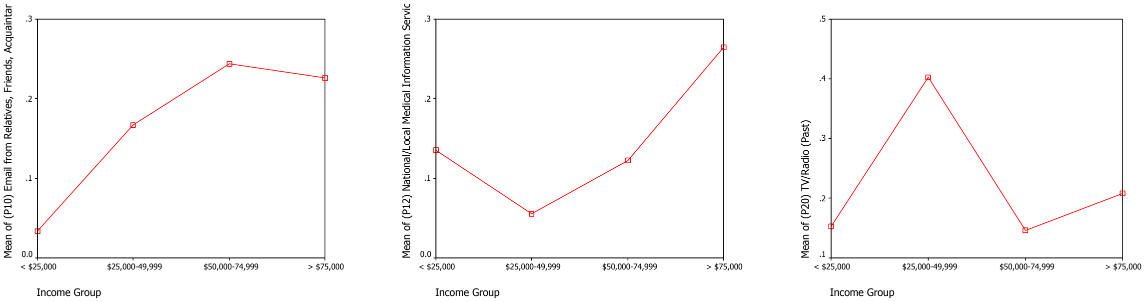


Figure 32: Patient Means Plots for Current Sources Use (1=Yes, 0=No) by Household Income (Group)

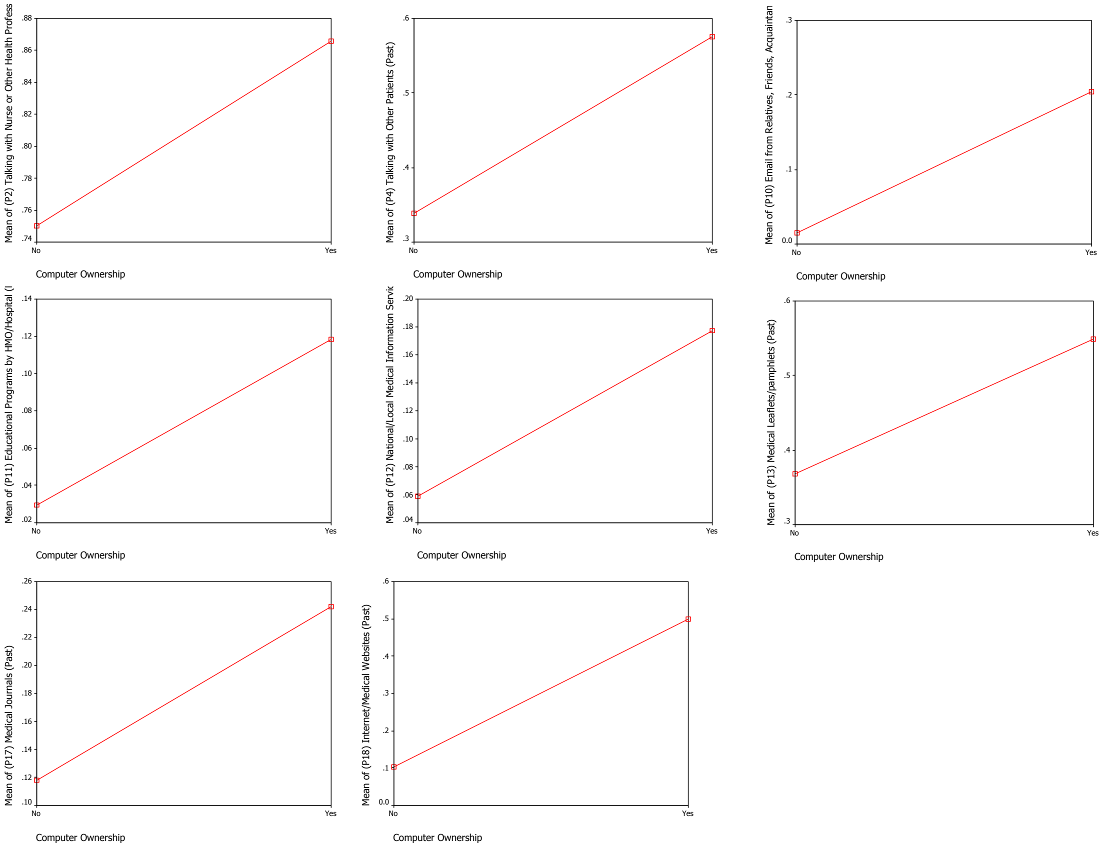


Figure 33: Patient Means Plots for Current Sources Use (1=Yes, 0=No) by Computer Ownership

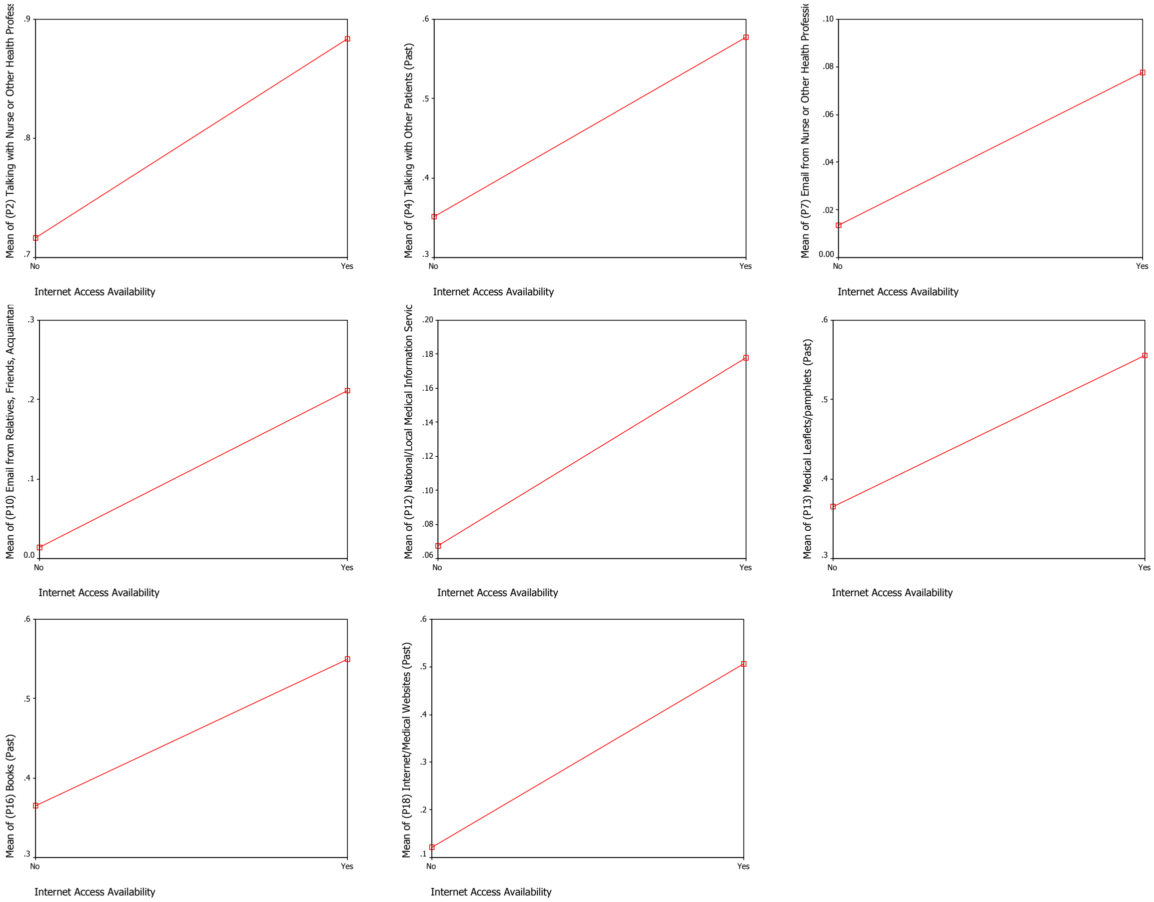


Figure 34: Patient Means Plots for Current Sources Use (1=Yes, 0=No) by Internet Access Availability

Table 42: Companion ANOVA for Demographics by Current Sources

Companion Current Sources	Demographics													
	Cancer Type N=167	Diagnosis Date N=167	Stage N=151	Gender N=167	Age N=166	Race N=166	Education N=165	Working Status N=152	Household Income N=148	Insurance N=161	Marital Status N=165	Children N=166	Computer Ownership N=167	Internet Access N=166
1 Talking with Physician or Physician's Assistant	.230	.907	.262	***.041***	.564	.738	.400	.542	.985	.513	.406	.432	.228	.247
2 Talking with Nurse or Other Health Professionals	.621	.088	.145	.952	.314	.586	.683	.927	.286	.675	.369	.070	.769	.480
3 Talking with a Support Group	***.015***	.633	.372	.140	.331	.447	.177	.559	.758	.956	.938	.186	.434	.282
4 Talking with Other Patients	***.036***	.265	.154	.442	.205	.421	.282	.640	.089	.460	.475	.431	.156	.145
5 Talking with Relatives, Friends, and Acquaintances	.335	.634	.055	***.022***	***.004***	.839	.578	***.047***	.682	.946	.236	.155	.085	.554
6 Email from Physician or Physician's Assistant	.996	.868	.244	.211	.518	.868	.858	.480	.123	.995	.486	.455	.180	.214
7 Email from Nurse or Other Health Professionals	.398	.591	.567	.813	.535	.907	.729	.715	.119	.384	.411	.390	.992	.921
8 Email or Chat-room with a Support Group	.451	.369	.269	.657	.564	.738	.812	.384	.824	.513	.406	.822	.859	.919
9 Email or Chat-room with Other Patients	.748	.520	.439	.630	.476	.831	.987	.438	.459	.625	.076	.355	.658	.606
10 Email from Relatives, Friends, and Acquaintances	.803	.739	.563	.553	.067	.806	***.003***	.480	***.037***	.612	.966	.252	***.035***	***.047***
11 Educational Programs by HMO or Hospital	.078	.248	.906	.771	***.035***	.901	.456	***.005***	.245	.325	.745	.661	.285	.630
12 National/Local Medical Information Services	.625	.542	.076	.825	.315	.555	.480	.846	.199	.188	.425	.762	.716	.966
13 Medical Leaflets or Pamphlets	.302	.191	.918	.128	.209	.883	.093	.084	.257	.774	.770	.678	.337	.070
14 Narratives	.741	.535	.183	.853	.444	.821	.770	.764	.350	.820	.514	.992	.495	.712
15 Message Board	.100	.945	.170	.140	.677	.916	.546	.345	.796	.384	.118	.940	.431	.921
16 Books	.903	.987	.489	.173	.424	.406	.773	.254	.829	.479	.122	.391	.759	.593
17 Medical Journals	.428	.402	.624	.064	.567	.072	.720	.301	.229	.312	.619	***.001***	.591	.776
18 Internet or Medical Websites	.192	.464	.133	.675	***.045***	.760	***.001***	.117	.117	.555	.417	.290	***.000***	***.000***
19 Telephone or Helpline	.760	.763	.170	.051	.798	.907	.432	.877	.117	.406	***.046***	.089	***.000***	.051
20 TV/Radio	.932	.252	.321	***.014***	.607	.377	.626	.923	.729	.055	.274	.950	.129	.706
21 Newspapers /Magazines	.922	.570	.341	.061	.752	.162	.570	.579	.198	.089	.529	.944	***.016***	.148
22 Audio/Video Tapes	.713	.053	.109	.656	.566	.467	.831	.272	.867	.733	.875	.336	.890	.977
23 Films/Movies	.353	.421	.812	***.008***	.231	.162	.806	.886	.478	.308	.021	***.026***	.104	.282

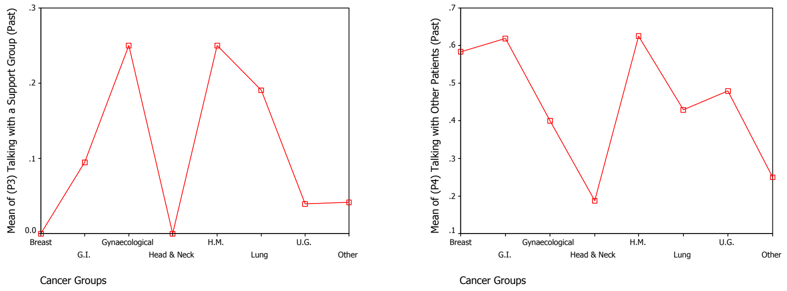


Figure 35: Companion Means Plots for Current Sources Use (1=Yes, 0=No) by Cancer Type (Group)

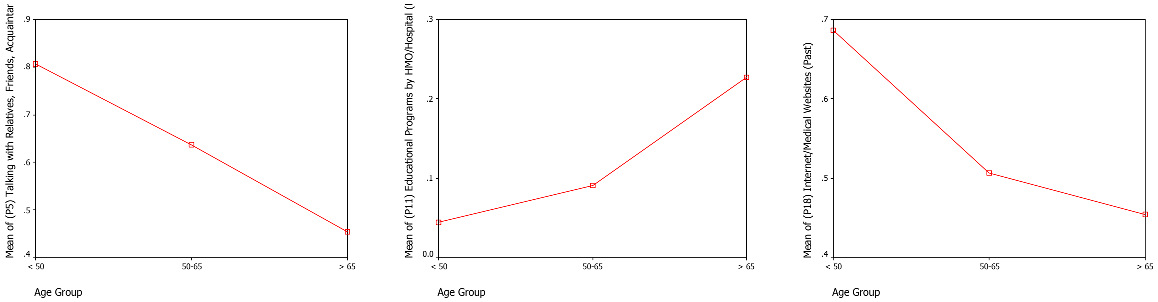


Figure 36: Companion Means Plots for Current Sources Use (1=Yes, 0=No) by Gender

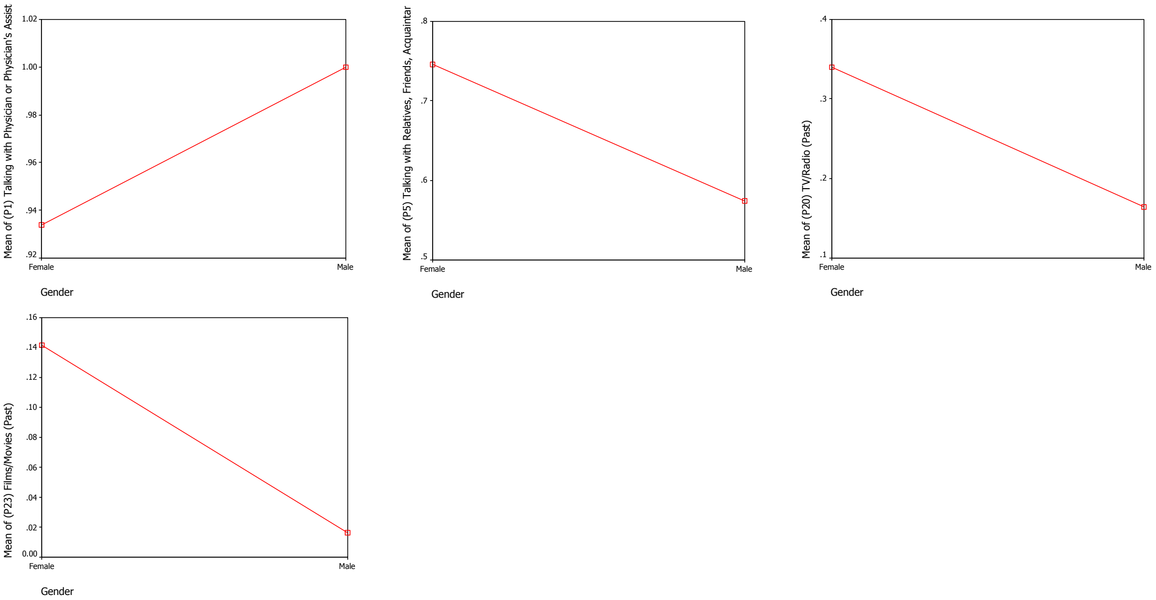


Figure 37: Companion Means Plots for Current Sources Use (1=Yes, 0=No) by Age (Group)

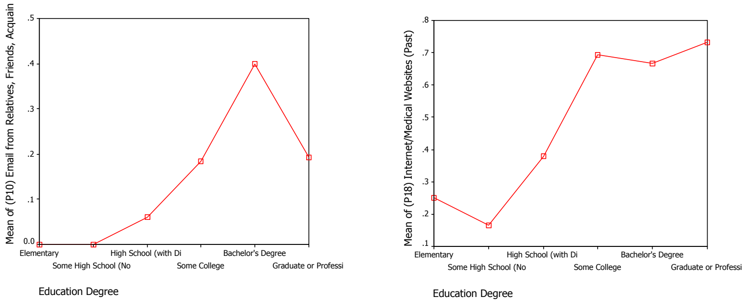


Figure 38: Companion Means Plots for Current Sources Use (1=Yes, 0=No) by Education

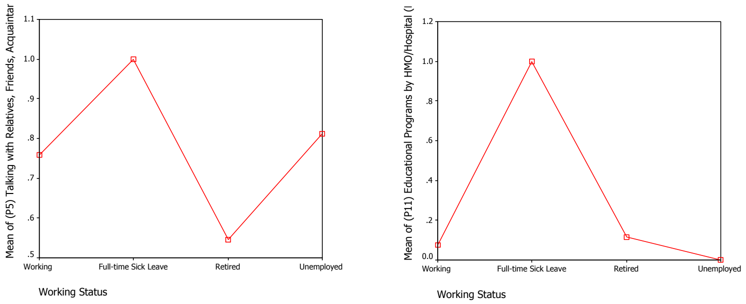


Figure 39: Companion Means Plots for Current Sources Use (1=Yes, 0=No) by Working Status

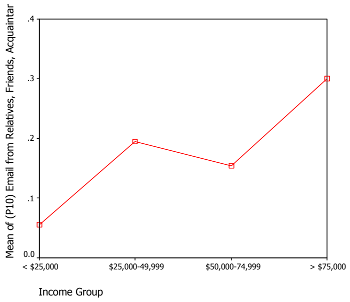


Figure 40: Companion Means Plots for Current Sources Use (1=Yes, 0=No) by Household Income (Group)

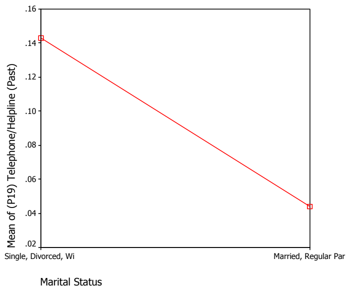


Figure 41: Companion Means Plots for Current Sources Use (1=Yes, 0=No) by Marital STATUS

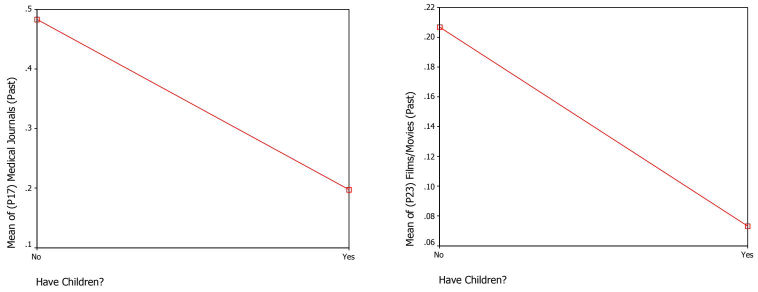


Figure 42: Companion Means Plots for Current Sources Use (1=Yes, 0=No) by Having Children Or Not

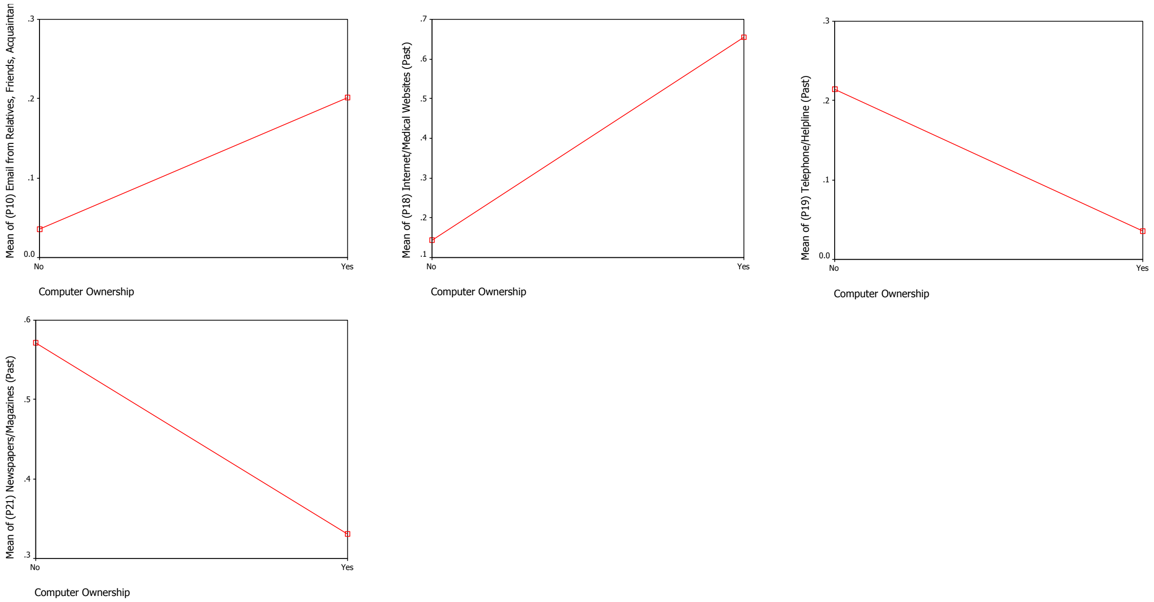


Figure 43: Companion Means Plots for Current Sources Use (1=Yes, 0=No) by Computer Ownership

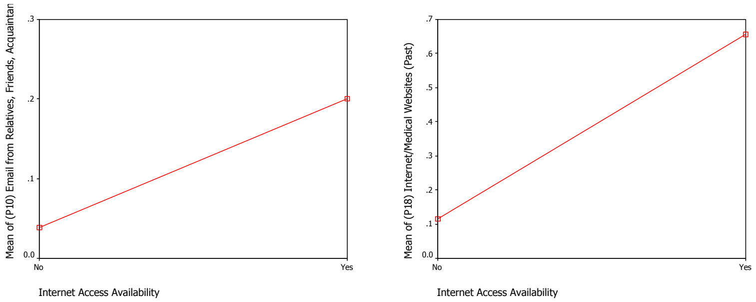


Figure 44: Companion Means Plots for Current Sources Use (1=Yes, 0=No) by Internet Access Availability

Table 43: Overall ANOVA for Demographics by Future Sources

	Demographics													
Future Sources	Cancer Type N=424	Diagnosis Date N=424	Stage N=386	Gender N=424	Age N=419	Race N=422	Education N=418	Working Status N=379	Household Income N=373	Insurance N=408	Marital Status N=417	Children N=421	Computer Ownership N=421	Internet Access N=420
1 Talking with Physician or Physician's Assistant	.111	.312	.450	.320	.271	.615	.238	.166	.191	.121	.208	.395	.930	.988
2 Talking with Nurse or Other Health Professionals	.657	.168	.456	.217	***.042***	.294	***.030***	.968	***.000***	.187	.669	***.011***	.098	***.040***
3 Talking with a Support Group	.258	.711	.680	.174	.163	***.000***	.324	.465	.649	.944	.073	.091	.976	.675
4 Talking with Other Patients	.071	.217	.849	***.045***	.121	.440	***.010***	.518	.482	.897	.857	.961	.334	.290
5 Talking with Relatives, Friends, and Acquaintances	.656	.300	.275	***.003***	***.012***	.657	.054	.141	.514	.905	.302	.350	.653	.266
6 Email from Physician or Physician's Assistant	.611	.315	.102	.886	.706	***.035***	.523	***.027***	.158	.445	.667	.902	***.005***	***.011***
7 Email from Nurse or Other Health Professionals	.899	.427	.070	.291	.156	***.032***	.601	.310	.973	.177	.411	.834	.041	.093
8 Email or Chat-room with a Support Group	.476	.437	.415	***.026***	***.025***	***.039***	.780	.115	.975	.062	***.020***	.664	.137	.115
9 Email or Chat-room with Other Patients	.212	.228	.204	.223	***.002***	***.003***	.817	***.015***	.571	***.040***	.251	.436	.228	.197
10 Email from Relatives, Friends, and Acquaintances	.101	.136	.392	***.013***	***.001***	.763	***.000***	***.004***	***.005***	.371	.836	.868	***.000***	***.000***
11 Educational Programs by HMO or Hospital	***.011***	.466	.379	***.012***	.536	***.000***	***.042***	.251	.519	.517	.352	.073	.441	.194
12 National/Local Medical Information Services	.165	.827	***.003***	.466	.640	***.000***	***.011***	.399	***.001***	.817	.926	.205	***.021***	***.005***
13 Medical Leaflets or Pamphlets	.458	.925	.739	***.011***	***.046***	.442	***.004***	.381	***.040***	.419	.921	.509	***.009***	***.000***
14 Narratives	***.045***	.815	.493	.061	***.004***	***.000***	.284	.090	.097	.388	.896	.426	.837	.337
15 Message Board	.141	.875	.316	***.045***	.071	.125	.564	.304	.873	.745	.090	.541	.524	.646
16 Books	.276	.574	.451	***.029***	.060	***.011***	***.000***	***.025***	.052	.854	***.007***	.091	.239	***.012***
17 Medical Journals	***.002***	.293	.853	***.018***	.598	***.004***	***.000***	.218	.453	.638	.938	.221	.135	***.022***
18 Internet or Medical Websites	***.046***	.440	.938	.107	***.000***	.130	***.000***	***.000***	***.011***	.657	.666	.650	***.000***	***.000***
19 Telephone or Helpline	.859	.953	.128	.532	.744	.194	.813	.880	.506	.395	.214	.351	.302	.903
20 TV/Radio	.280	.165	.602	***.042***	.897	.066	.734	.425	***.003***	.583	.066	.492	.078	.518
21 Newspapers /Magazines	***.004***	.090	.276	***.004***	.912	***.038***	.055	.786	***.019***	.275	.123	.592	.675	.691
22 Audio/Video Tapes	.810	.404	.275	.496	.116	***.043***	.467	.431	***.034***	.383	.714	.125	.526	.458
23 Films/Movies	.838	.933	.688	.751	***.010***	.225	.901	.456	.545	.812	.066	.104	.606	.928

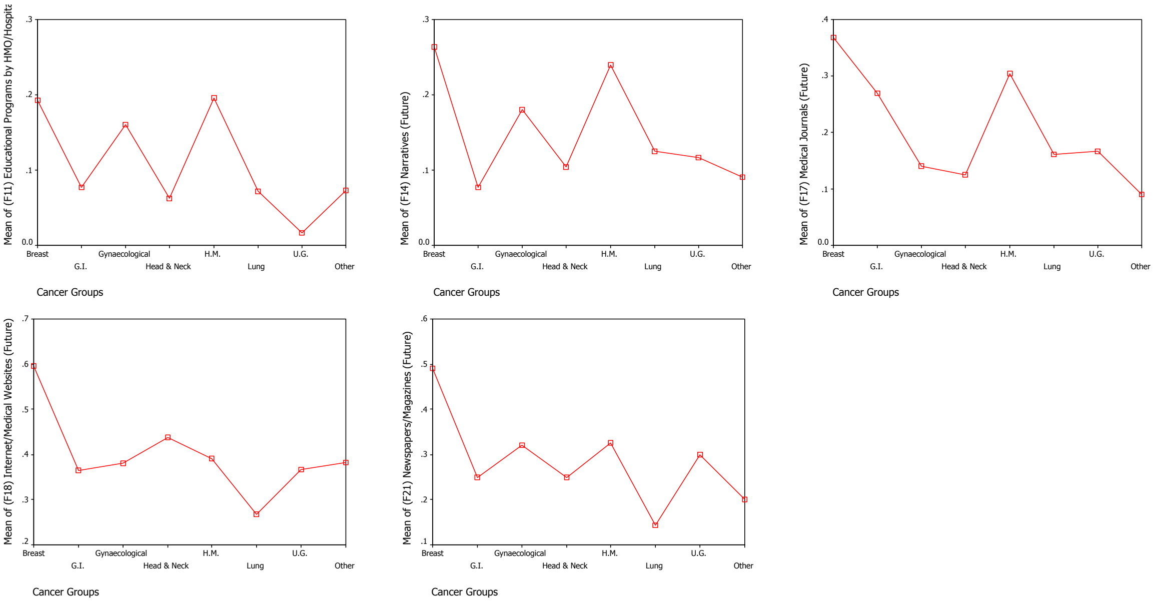


Figure 45: Overall Means Plots for Future Sources Use (1=Yes, 0=No) by Cancer Type (Group)

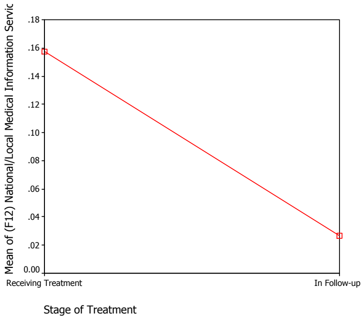


Figure 46: Overall Means Plots for Future Sources Use (1=Yes, 0=No) by Stage

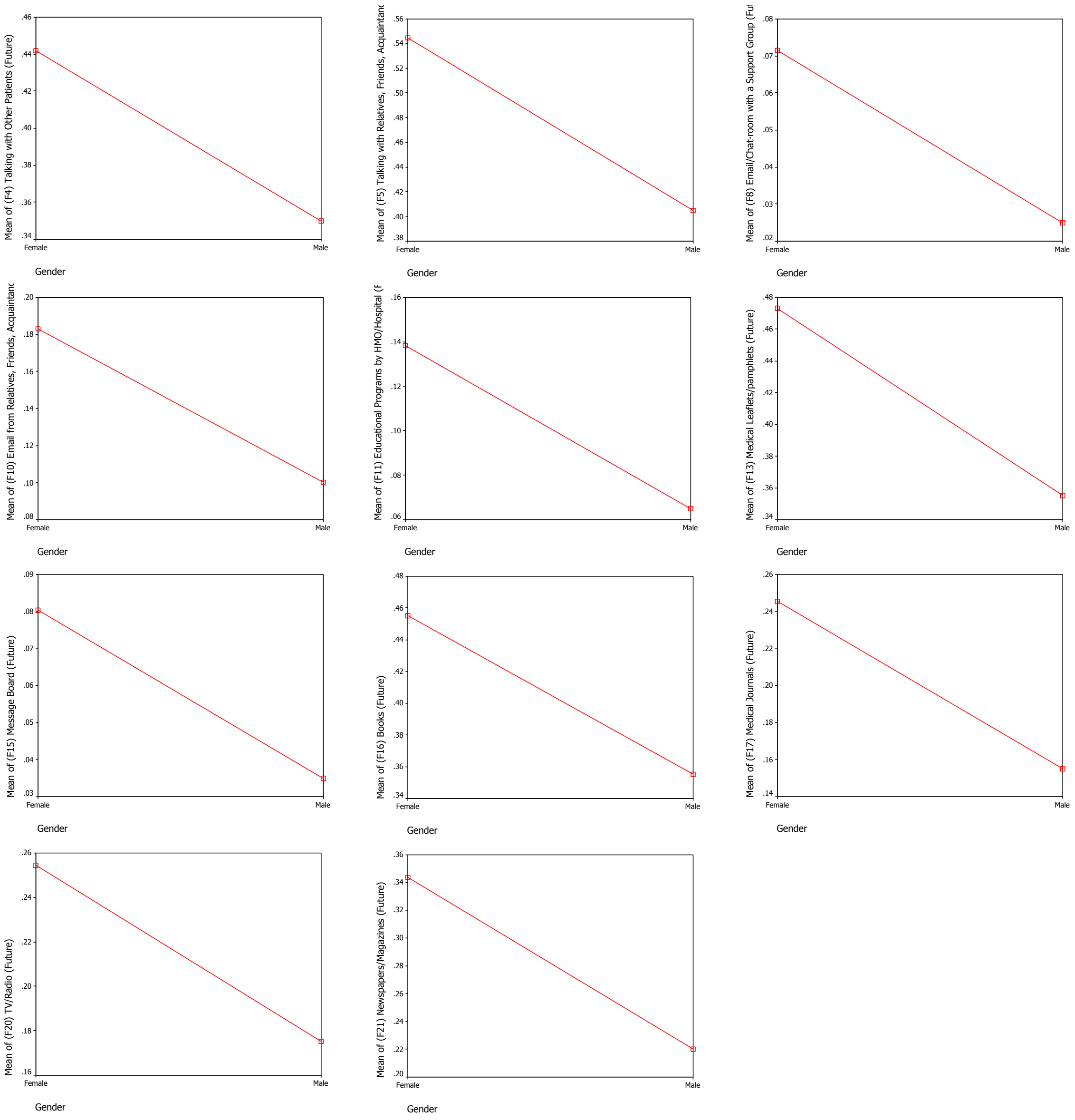


Figure 47: Overall Means Plots for Future Sources Use (1=Yes, 0=No) by Gender

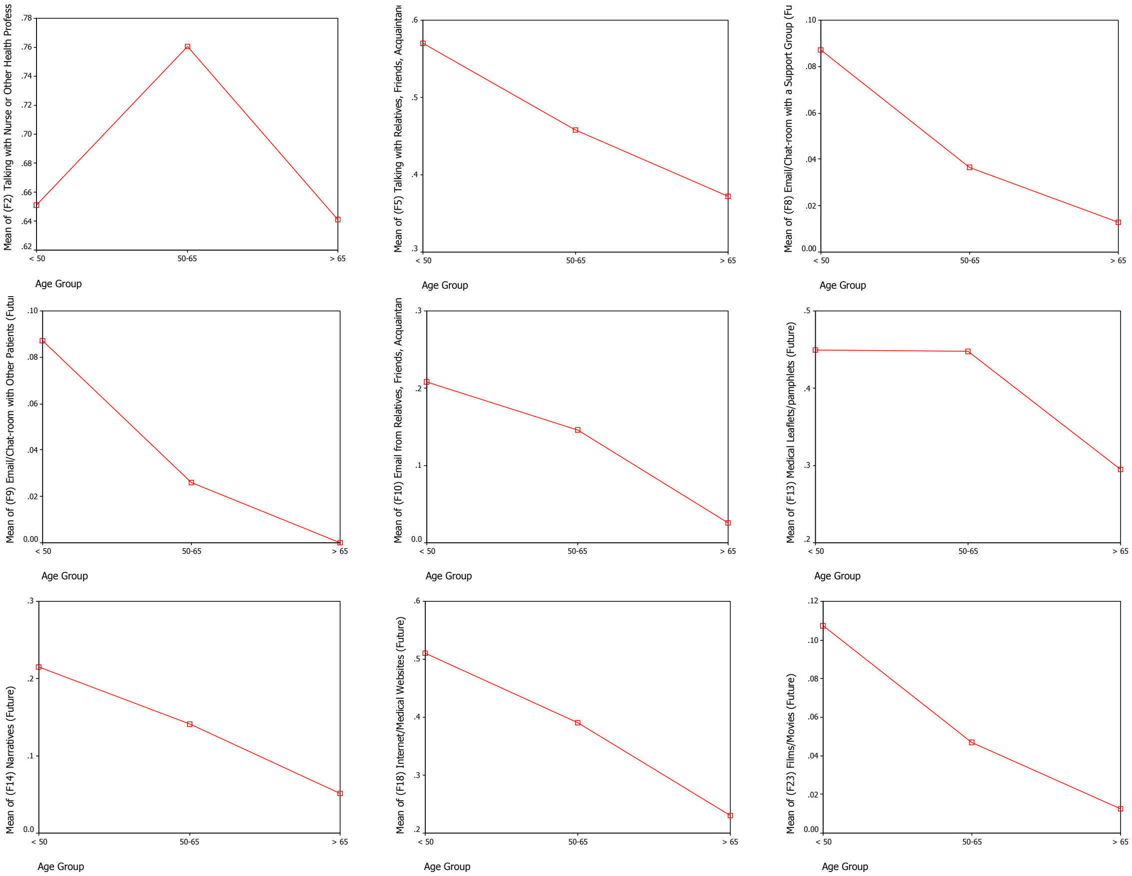


Figure 48: Overall Means Plots for Future Sources Use (1=Yes, 0=No) by Age (Group)

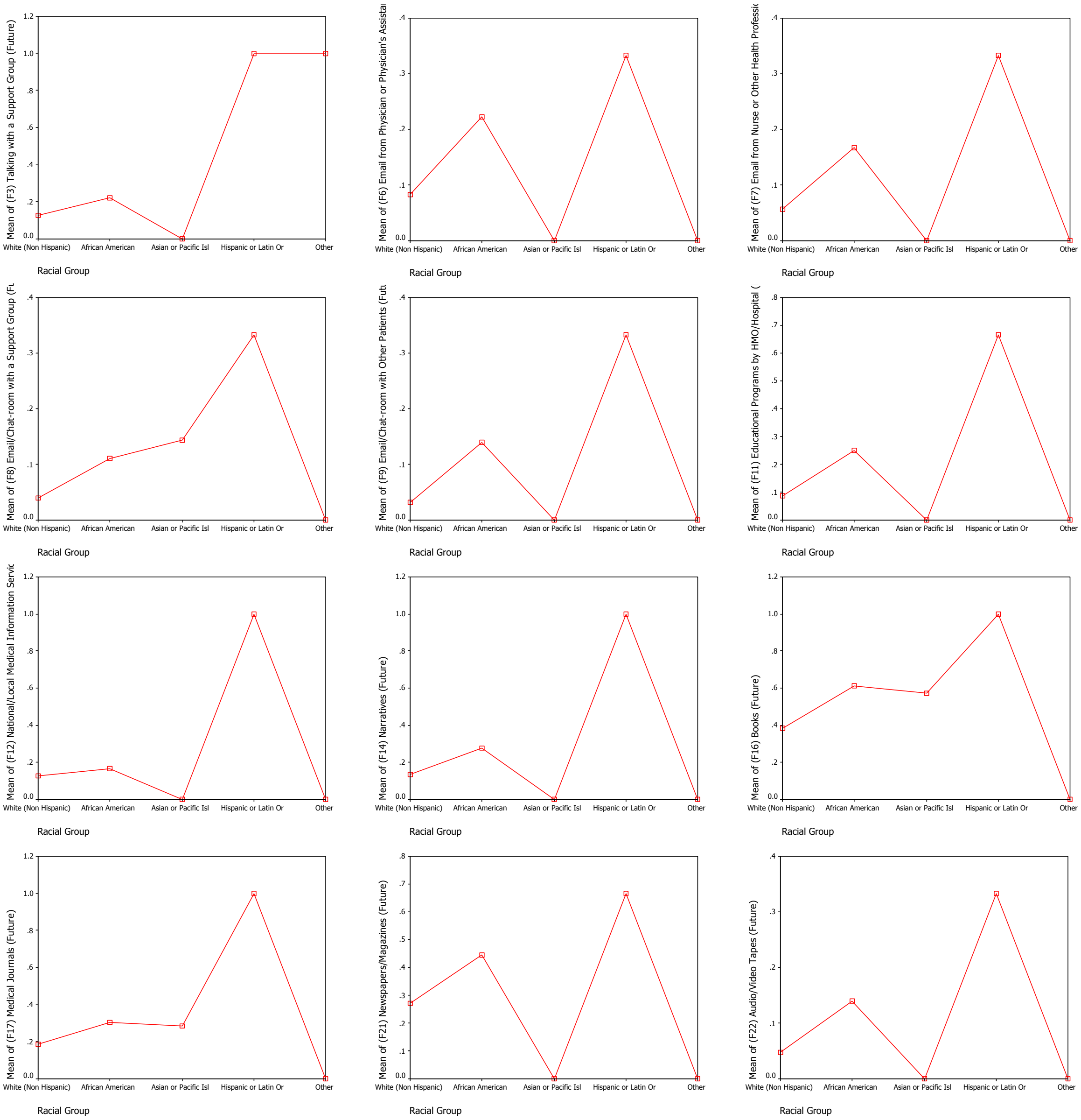


Figure 49: Overall Means Plots for Future Sources Use (1=Yes, 0=No) by Race

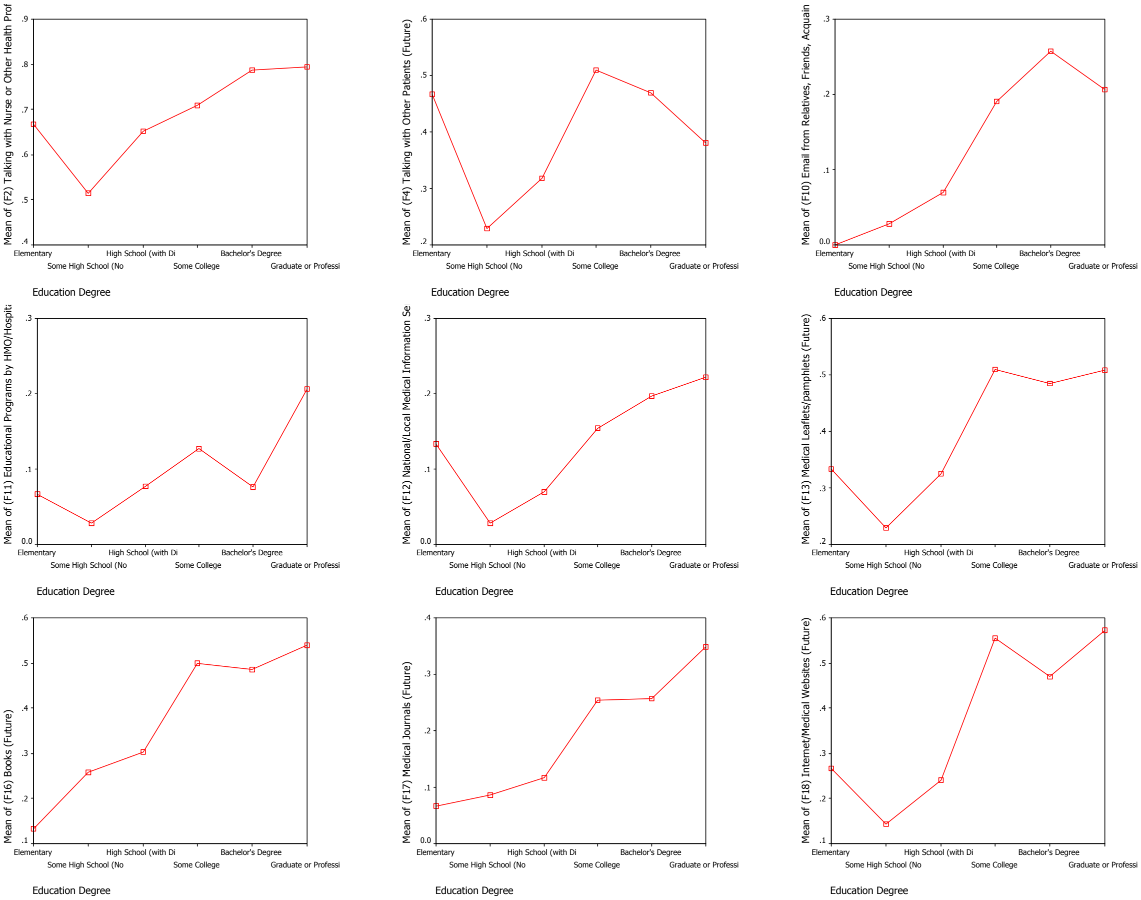


Figure 50: Overall Means Plots for Future Sources Use (1=Yes, 0=No) by Education

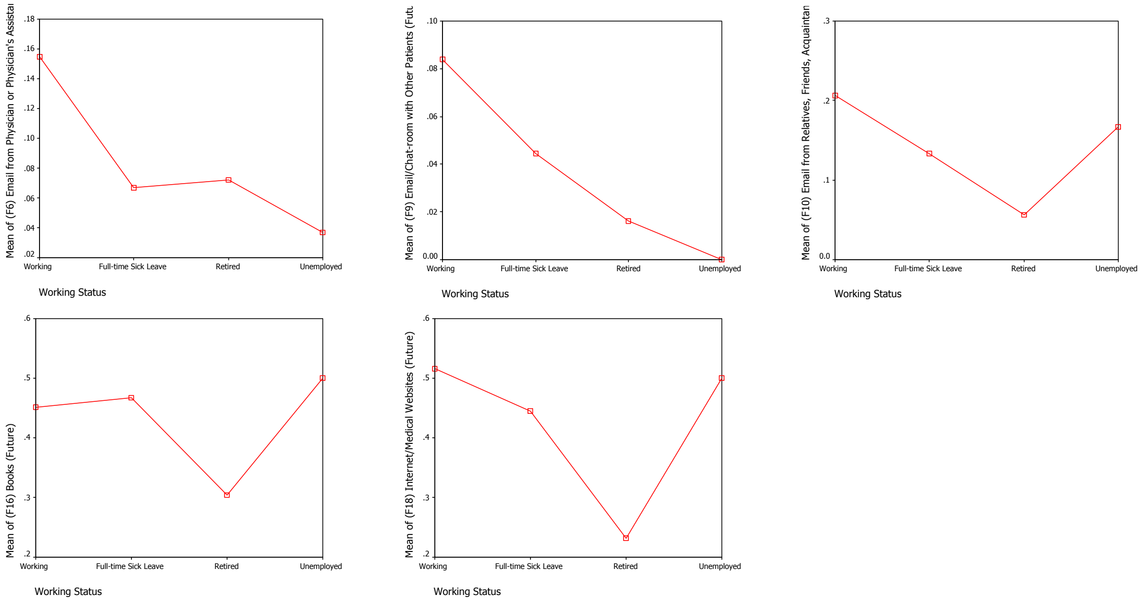


Figure 51: Overall Means Plots for Future Sources Use (1=Yes, 0=No) by Working Status

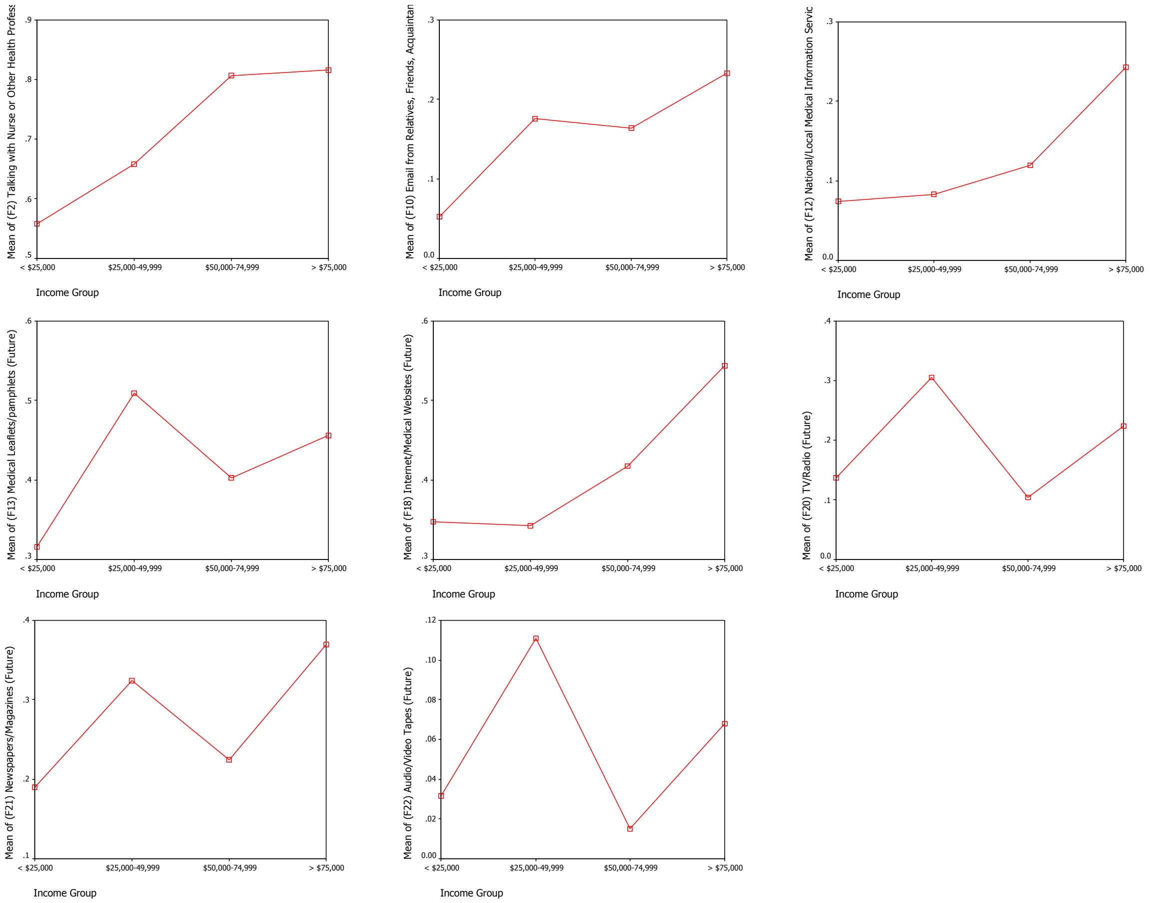


Figure 52: Overall Means Plots for Future Sources Use (1=Yes, 0=No) by Household Income (Group)

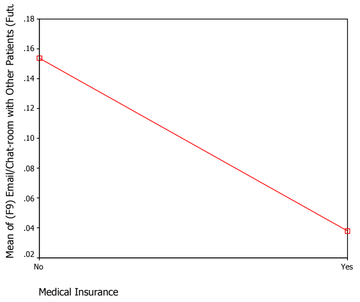


Figure 53: Overall Means Plots for Future Sources Use (1=Yes, 0=No) by Insurance

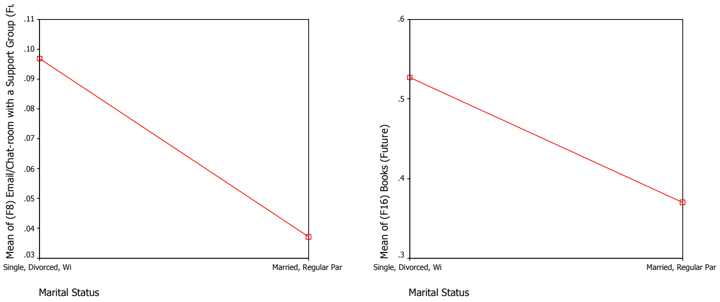


Figure 54: Overall Means Plots for Future Sources Use (1=Yes, 0=No) by Marital Status

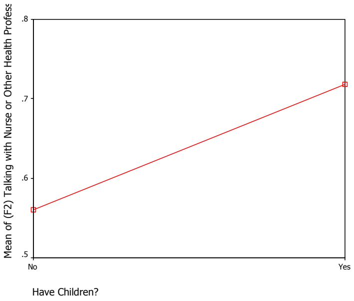


Figure 55: Overall Means Plots for Future Sources Use (1=Yes, 0=No) by Having Children Or Not

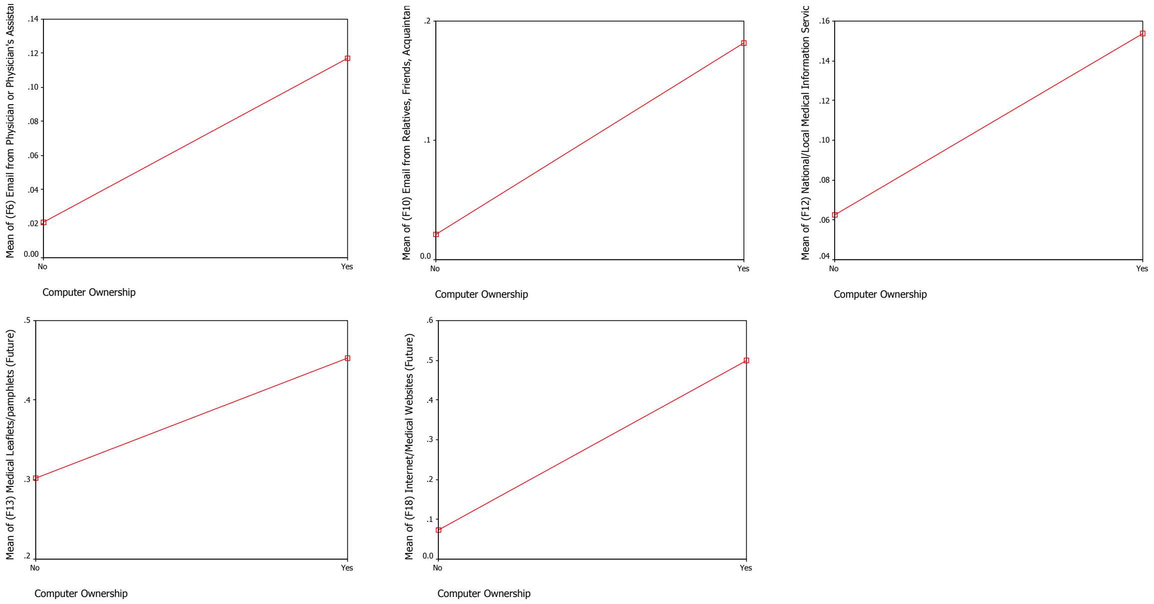


Figure 56: Overall Means Plots for Future Sources Use (1=Yes, 0=No) by Computer Ownership

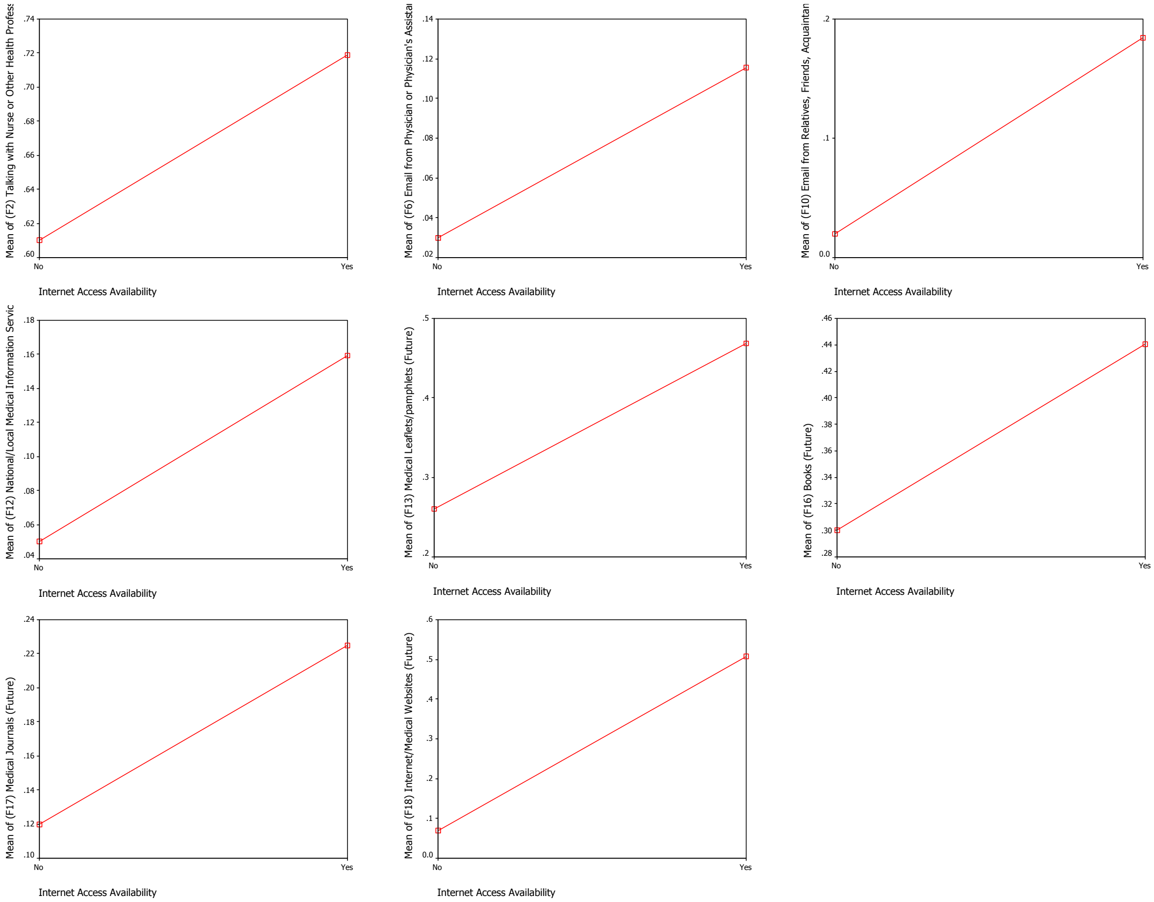


Figure 57: Overall Means Plots for Future Sources Use (1=Yes, 0=No) by Internet Access Availability

Table 44: Patient ANOVA for Demographics by Future Sources

Patient Future Sources	Demographics													
	Cancer Type N=257	Diagnosis Date N=257	Stage N=235	Gender N=257	Age N=253	Race N=256	Education N=253	Working Status N=227	Household Income N=225	Insurance N=247	Marital Status N=252	Children N=255	Computer Ownership N=254	Internet Access N=254
1 Talking with Physician or Physician's Assistant	***.048***	.991	.578	.062	.394	.405	.457	.358	.320	.533	.532	.460	.446	.488
2 Talking with Nurse or Other Health Professionals	.863	.623	.467	.284	.106	.352	***.030***	.732	***.002***	.368	.372	***.012***	.240	.075
3 Talking with a Support Group	.087	.715	.089	.343	***.023***	***.000***	.460	.374	.117	.573	.200	.216	.945	.680
4 Talking with Other Patients	***.039***	.676	.260	.260	.132	.631	***.005***	.112	.745	.787	.747	.731	***.040***	***.031***
5 Talking with Relatives, Friends, and Acquaintances	.423	.410	.100	.172	.185	.573	.044	.643	.507	.916	.342	.386	.911	.241
6 Email from Physician or Physician's Assistant	.473	.206	.595	.559	.665	.111	.171	.533	.344	.610	.356	.741	***.044***	.104
7 Email from Nurse or Other Health Professionals	.970	.624	.449	.837	.232	.109	.717	.966	.833	.665	.286	.927	.112	.264
8 Email or Chat-room with a Support Group	.562	.313	.795	.219	.245	***.027***	.764	.865	.610	.696	.129	.725	.177	.136
9 Email or Chat-room with Other Patients	.428	.204	.855	.825	***.024***	***.009***	.640	.465	.520	.773	.671	.880	.573	.498
10 Email from Relatives, Friends, and Acquaintances	***.004***	.119	.711	***.008***	***.035***	.679	***.003***	.060	.064	.464	.577	.787	***.001***	***.001***
11 Educational Programs by HMO or Hospital	***.016***	.476	.955	***.012***	.374	***.010***	***.014***	.094	.232	.322	.631	.272	.260	.165
12 National/Local Medical Information Services	.098	.707	***.043***	.061	.692	***.000***	***.025***	.518	.080	.430	.577	.416	.063	***.034***
13 Medical Leaflets or Pamphlets	.133	.501	.906	.128	.109	.261	.066	.835	.060	.634	.715	.657	.070	***.015***
14 Narratives	***.007***	.543	.694	.139	***.011***	***.001***	.149	.166	.081	.059	.225	.648	.708	.271
15 Message Board	.433	.296	.798	.148	***.029***	.116	.953	.670	.765	.059	.808	.981	.876	.516
16 Books	***.037***	.774	.367	.187	.060	***.013***	***.000***	***.031***	.076	.697	.096	.143	.304	***.049***
17 Medical Journals	***.003***	.418	.795	.134	.572	***.011***	***.001***	.694	.175	.795	.896	.576	.140	***.028***
18 Internet or Medical Websites	***.027***	.882	.237	.371	***.001***	.056	***.001***	***.001***	.222	.691	.982	.888	***.000***	***.000***
19 Telephone or Helpline	.624	.980	.375	.784	.765	.152	.359	.957	.820	.665	.543	.829	.888	.748
20 TV/Radio	.089	.452	.721	.449	.962	.060	.753	.459	***.015***	.162	.127	.394	.142	.320
21 Newspapers /Magazines	***.000***	.335	***.017***	.059	.545	.173	***.033***	.634	.247	.357	.276	.774	.953	.866
22 Audio/Video Tapes	.953	.706	.595	.883	.277	.198	.678	.678	.076	.623	.819	.376	.543	.424
23 Films/Movies	.487	.709	.297	.132	.050	.308	.752	.513	.449	.075	.543	.981	.876	.962

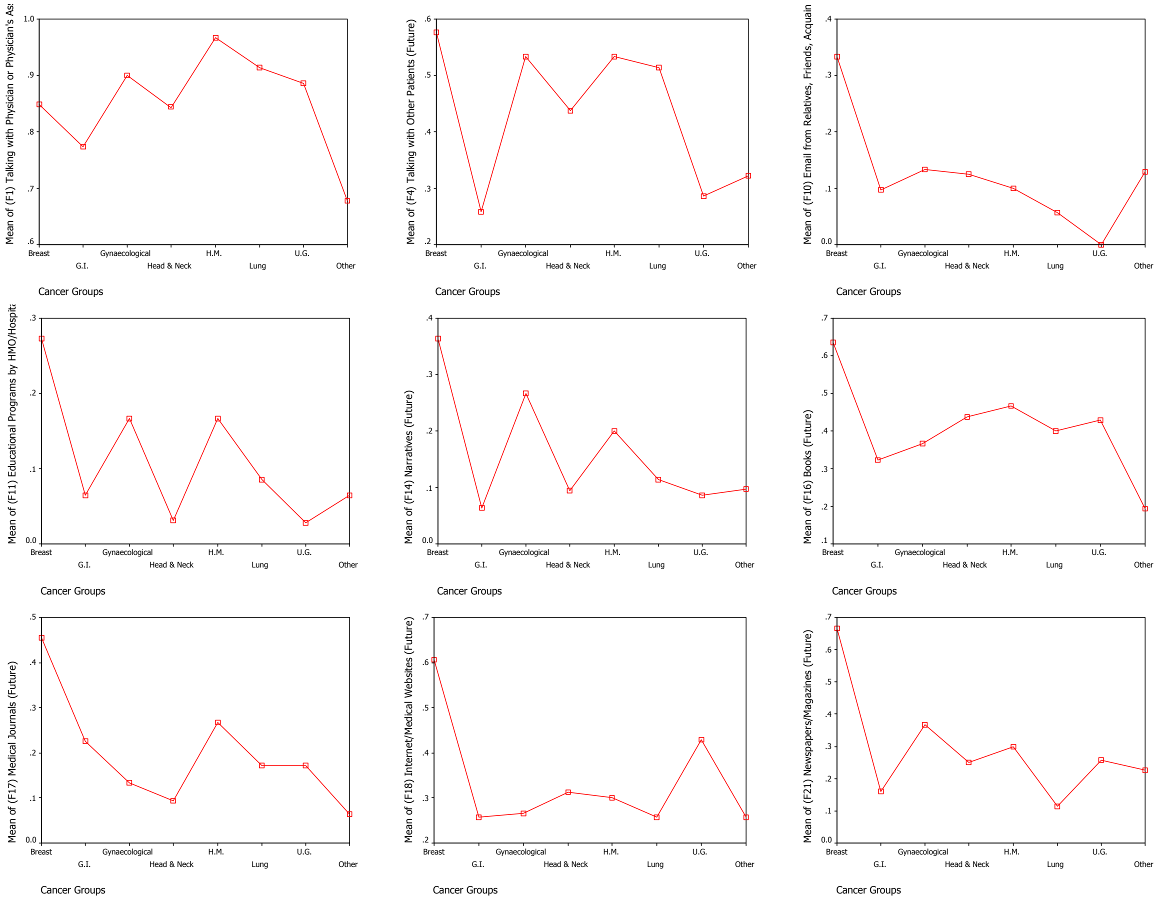


Figure 58: Patient Means Plots for Future Sources Use (1=Yes, 0=No) by Cancer Type (Group)

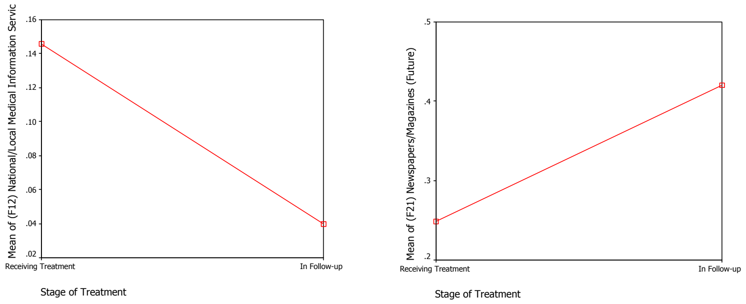


Figure 59: Patient Means Plots for Future Sources Use (1=Yes, 0=No) by Stage

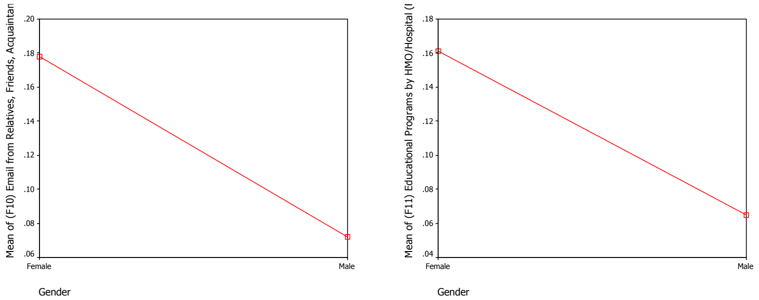


Figure 60: Patient Means Plots for Future Sources Use (1=Yes, 0=No) by Gender

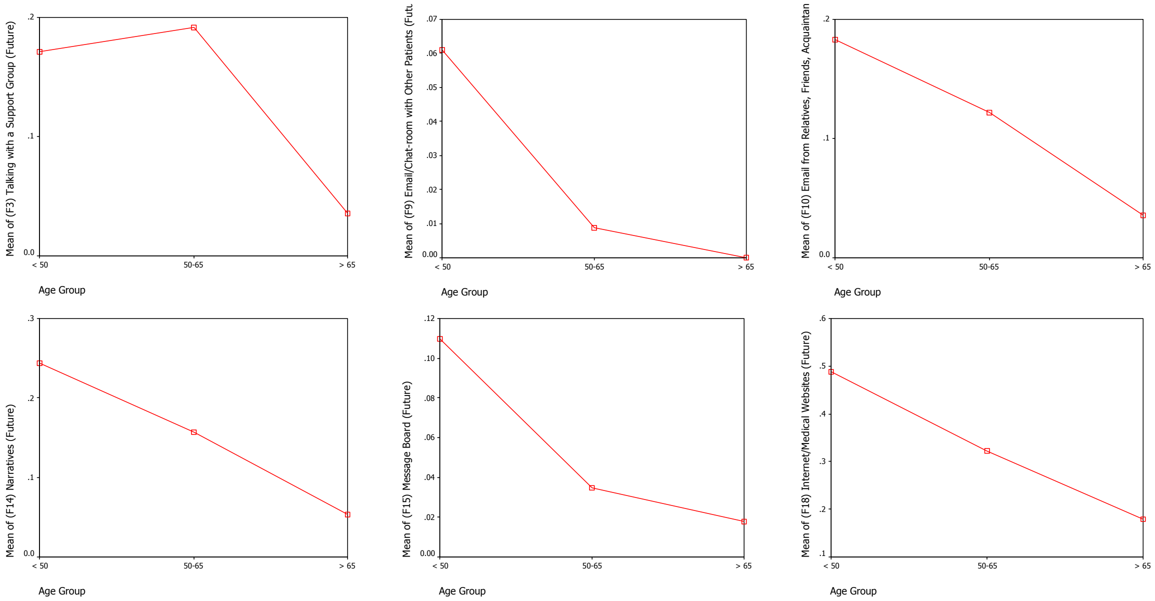


Figure 61: Patient Means Plots for Future Sources Use (1=Yes, 0=No) by Age (Group)

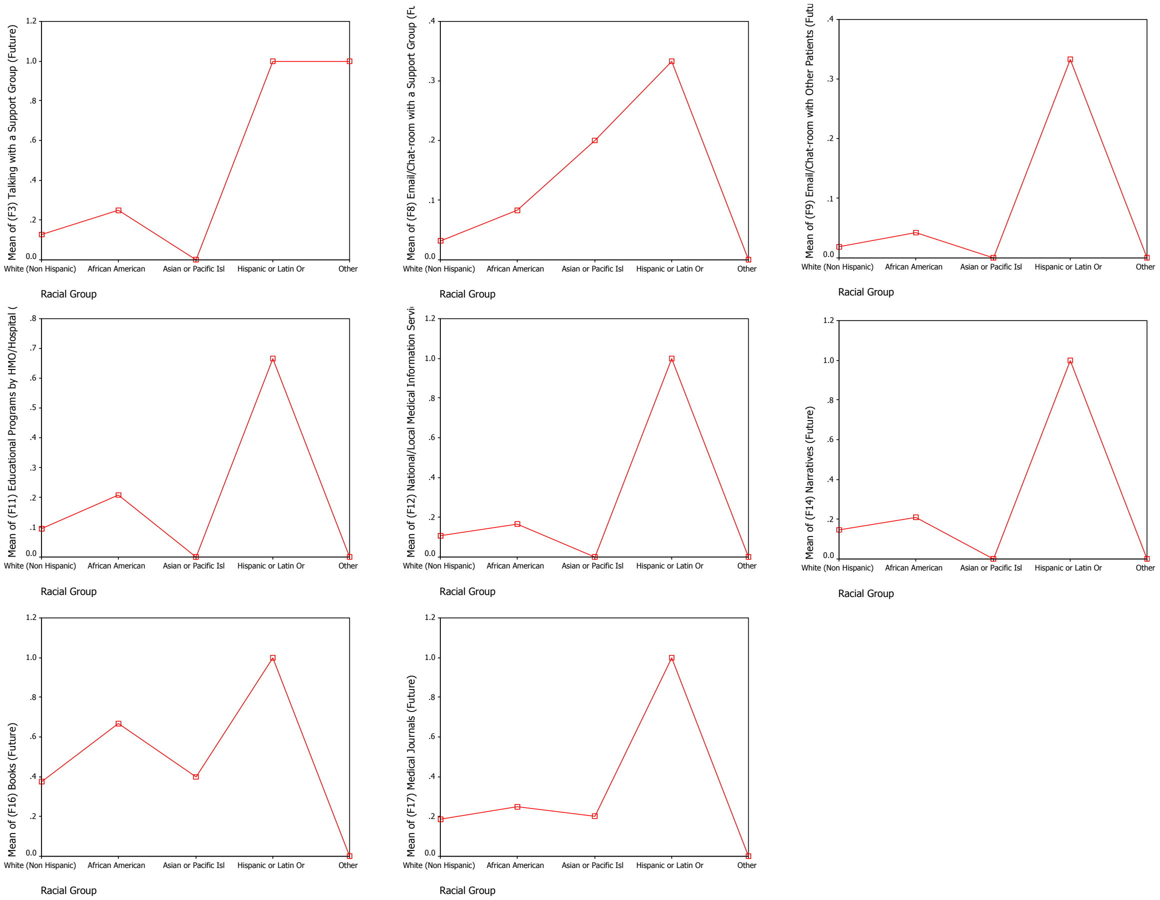


Figure 62: Patient Means Plots for Future Sources Use (1=Yes, 0=No) by Race

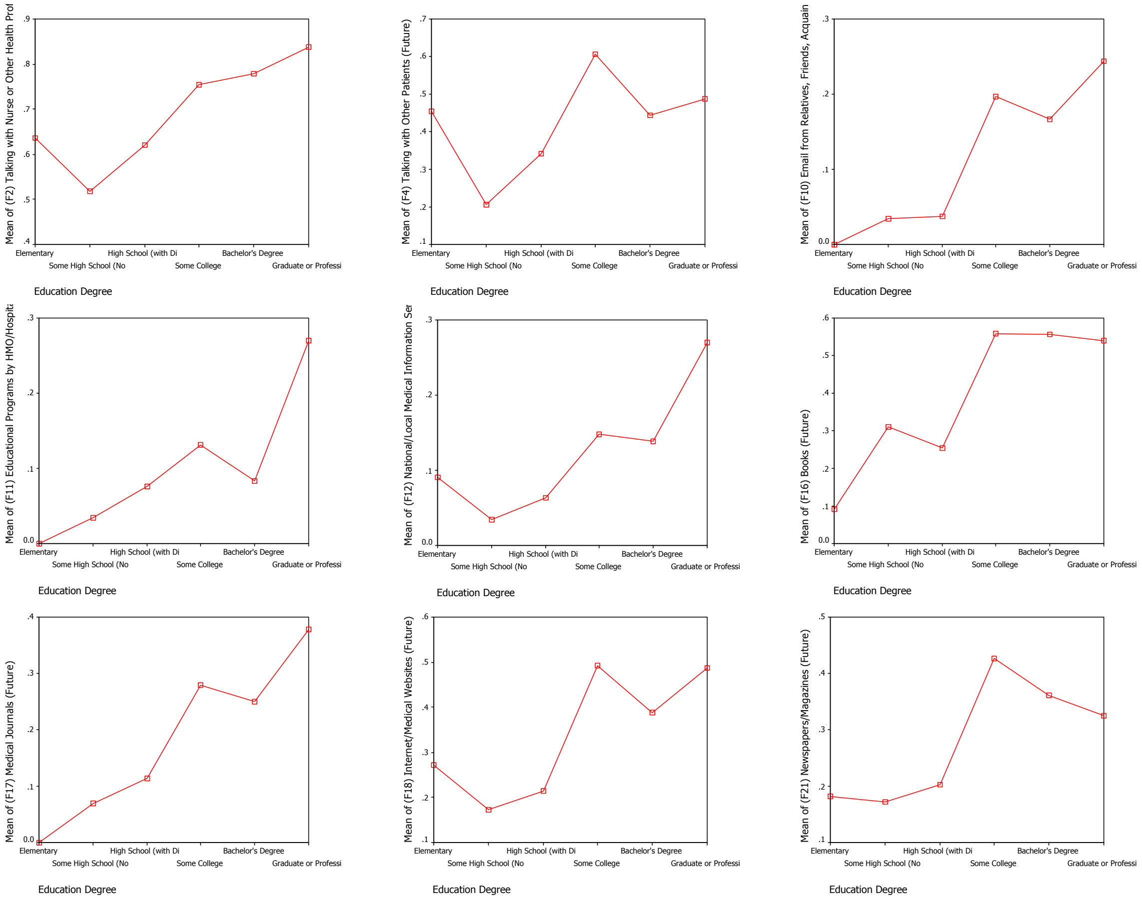


Figure 63: Patient Means Plots for Future Sources Use (1=Yes, 0=No) by Education

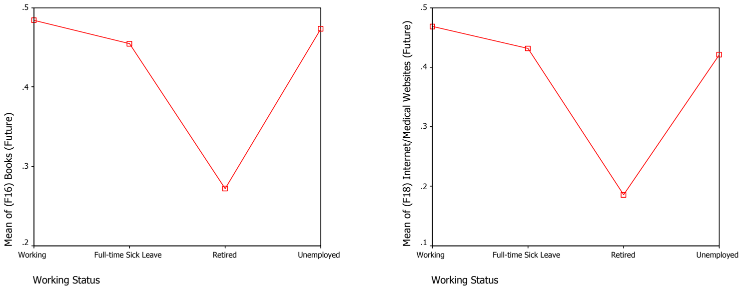


Figure 64: Patient Means Plots for Future Sources Use (1=Yes, 0=No) by Working Status

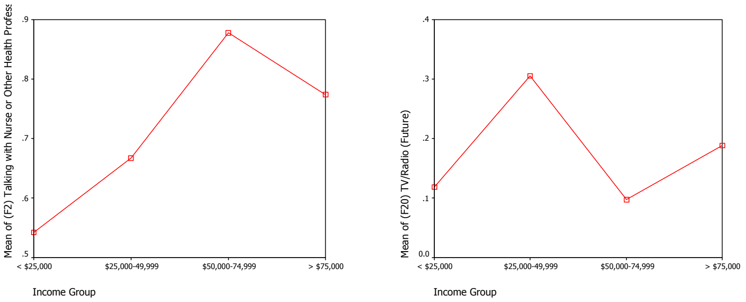


Figure 65: Patient Means Plots for Future Sources Use (1=Yes, 0=No) by Household Income (Group)

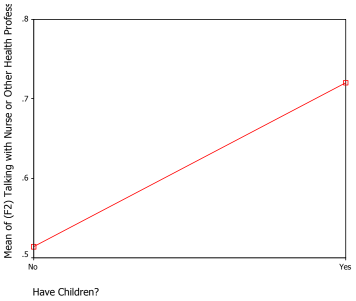


Figure 66: Patient Means Plots for Future Sources Use (1=Yes, 0=No) by Having Children Or Not

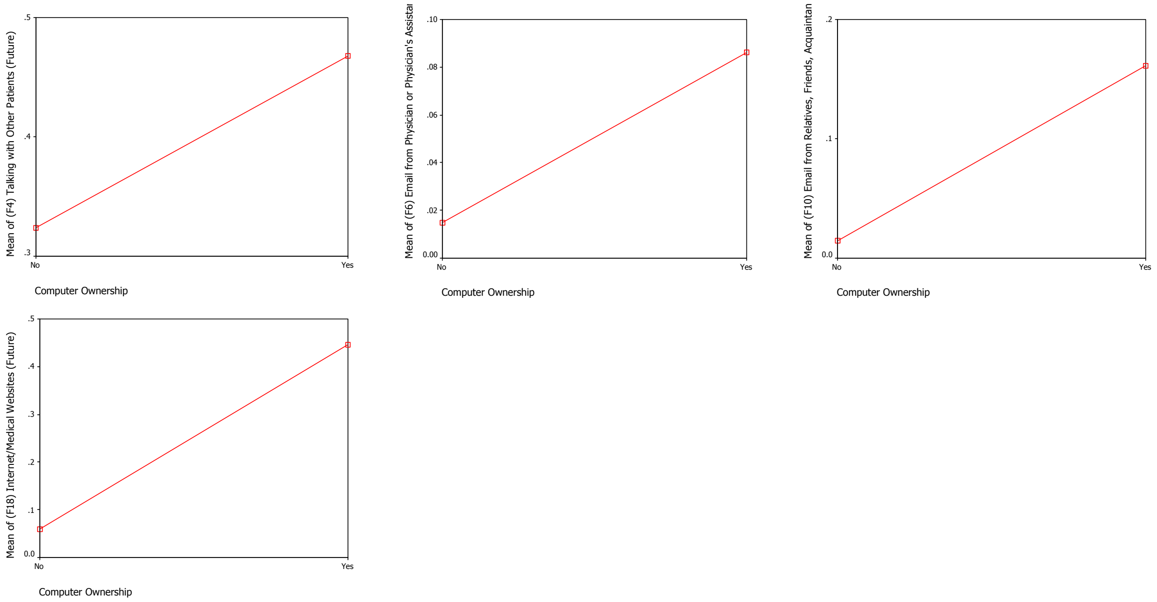


Figure 67: Patient Means Plots for Future Sources Use (1=Yes, 0=No) by Computer Ownership

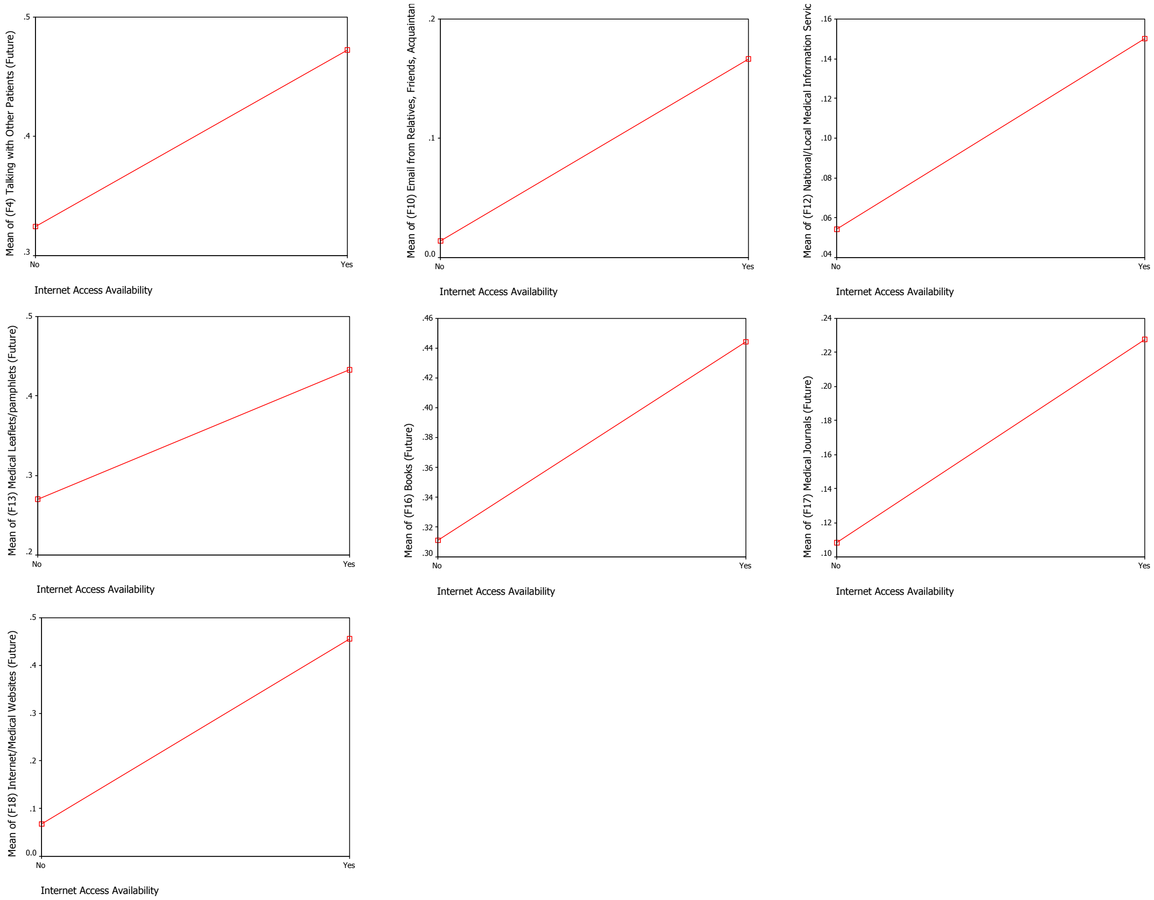


Figure 68: Patient Means Plots for Future Sources Use (1=Yes, 0=No) by Internet Access Availability

Table 45: Companion ANOVA for Demographics by Future Sources

Companion Future Sources	Demographics													
	Cancer Type N=167	Diagnosis Date N=167	Stage N=151	Gender N=167	Age N=166	Race N=166	Education N=165	Working Status N=152	Household Income N=148	Insurance N=161	Marital Status N=165	Children N=166	Computer Ownership N=167	Internet Access N=166
1 Talking with Physician or Physician's Assistant	.801	.122	***.044***	.691	.487	.661	.327	.212	.118	.196	.264	.689	.291	.204
2 Talking with Nurse or Other Health Professionals	.826	.112	***.023***	.545	.346	.445	.668	.727	***.026***	.326	.553	.316	.239	.316
3 Talking with a Support Group	.484	.282	.052	.266	.704	.810	.149	.835	.692	.781	.212	.244	.932	.780
4 Talking with Other Patients	.276	.128	***.034***	***.015***	.481	.523	.277	.459	.204	.894	.618	.656	.325	.354
5 Talking with Relatives, Friends, and Acquaintances	.189	.535	.689	***.002***	***.033***	.879	.864	***.043***	.951	.806	.605	.677	.319	.822
6 Email from Physician or Physician's Assistant	.523	.868	.119	.853	.989	.093	.861	.214	.512	.487	.954	.992	.087	.109
7 Email from Nurse or Other Health Professionals	.725	.545	.094	.165	.708	.095	.602	.208	.956	.173	.745	.661	.275	.318
8 Email or Chat-room with a Support Group	.366	.962	.170	.073	.115	.265	.922	.190	.748	***.041***	***.046***	.829	.557	.614
9 Email or Chat-room with Other Patients	.188	.591	.127	.392	.112	***.001***	.898	.136	.664	.083	.118	.479	.420	.471
10 Email from Relatives, Friends, and Acquaintances	.742	.620	.453	.691	***.041***	.661	.060	.226	.056	.246	.961	.689	***.030***	***.040***
11 Educational Programs by HMO or Hospital	.294	.784	.094	.317	.690	***.014***	.761	***.030***	.758	.904	.371	.128	.825	.716
12 National/Local Medical Information Services	.603	.937	***.024***	.199	.832	.830	.264	.720	***.037***	.744	.475	.354	.206	.083
13 Medical Leaflets or Pamphlets	.488	.483	.797	.078	.126	.941	.264	.377	.380	.133	.978	.555	.091	***.008***
14 Narratives	.472	.658	***.044***	.151	.240	***.009***	.746	.588	.431	.860	***.047***	.058	.425	.780
15 Message Board	.221	.337	.198	.193	.892	.334	.107	.292	.244	.406	***.009***	.379	.337	.813
16 Books	.150	.591	.977	.057	.701	.170	.252	.358	.384	.607	***.017***	.381	.557	.114
17 Medical Journals	.410	.502	.542	.059	.688	.110	.469	.075	.870	.429	.976	***.014***	.661	.441
18 Internet or Medical Websites	.092	.148	.261	.533	.373	.792	***.000***	***.018***	.128	.691	.813	.730	***.000***	***.000***
19 Telephone or Helpline	.968	.962	.198	.266	.961	.887	.800	.963	.515	.430	.181	.285	***.043***	.699
20 TV/Radio	.413	.203	.709	***.016***	.685	.733	.828	.853	.244	.105	.299	***.003***	.325	.743
21 Newspapers /Magazines	.642	.134	.151	***.014***	.714	.131	.415	.344	***.012***	.051	.274	.639	.553	.568
22 Audio/Video Tapes	.433	.357	.230	.420	.324	.135	.860	.428	.383	.483	.732	.184	.742	.802
23 Films/Movies	.266	.591	.567	***.035***	.185	.402	.942	.749	.761	.384	***.018***	***.022***	.431	.921

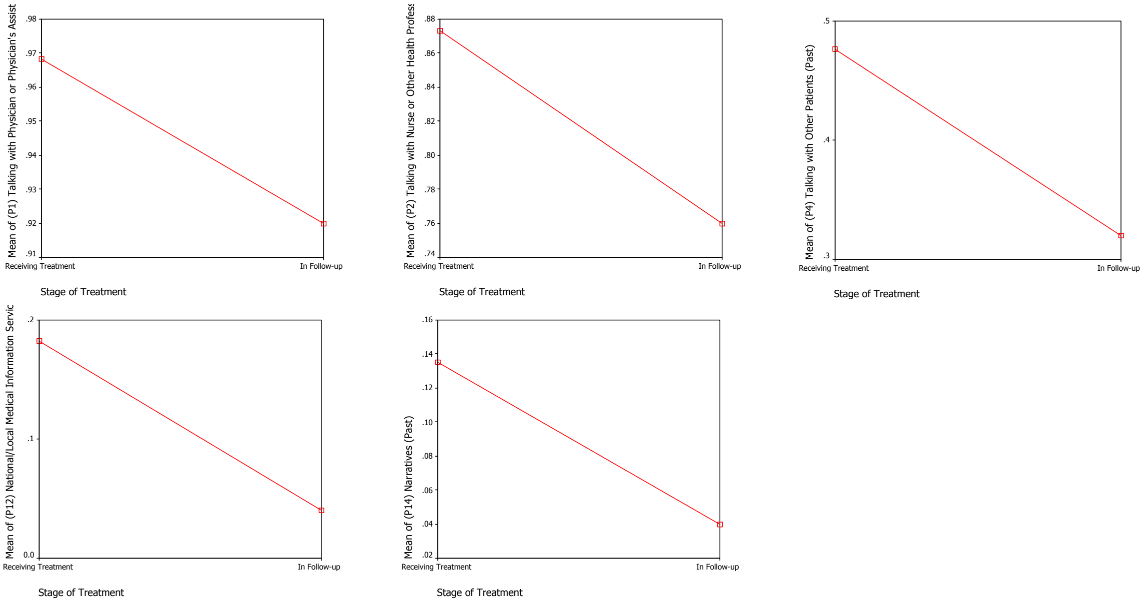


Figure 69: Companion Means Plots for Future Sources Use (1=Yes, 0=No) by Stage

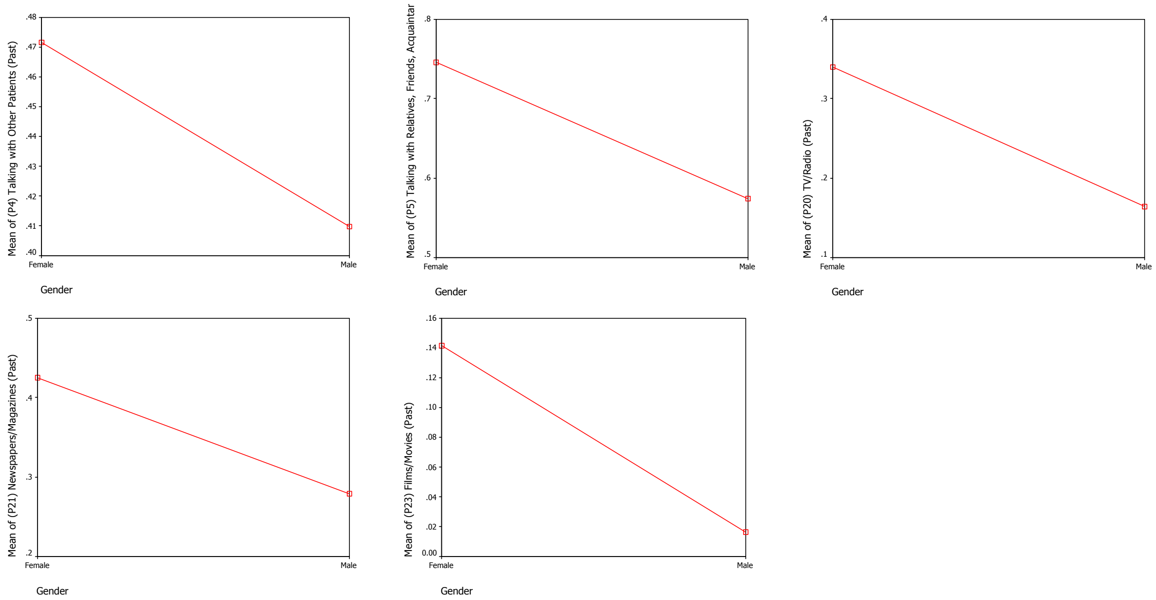


Figure 70: Companion Means Plots for Future Sources Use (1=Yes, 0=No) by Gender

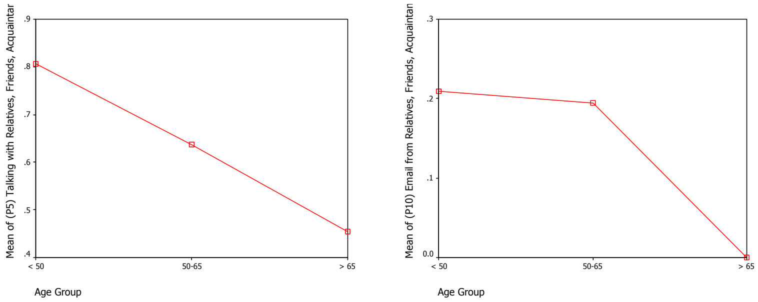


Figure 71: Companion Means Plots for Future Sources Use (1=Yes, 0=No) by Age (Group)

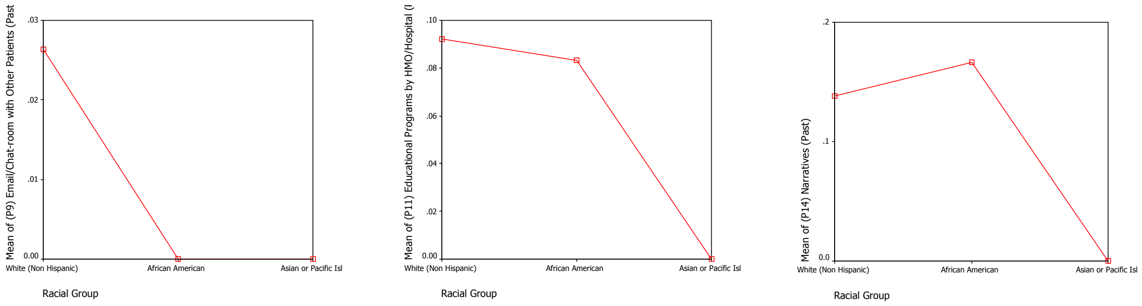


Figure 72: Companion Means Plots for Future Sources Use (1=Yes, 0=No) by Race

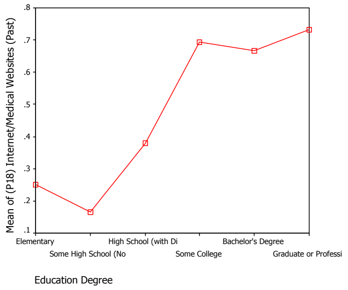


Figure 73: Companion Means Plots for Future Sources Use (1=Yes, 0=No) by Education

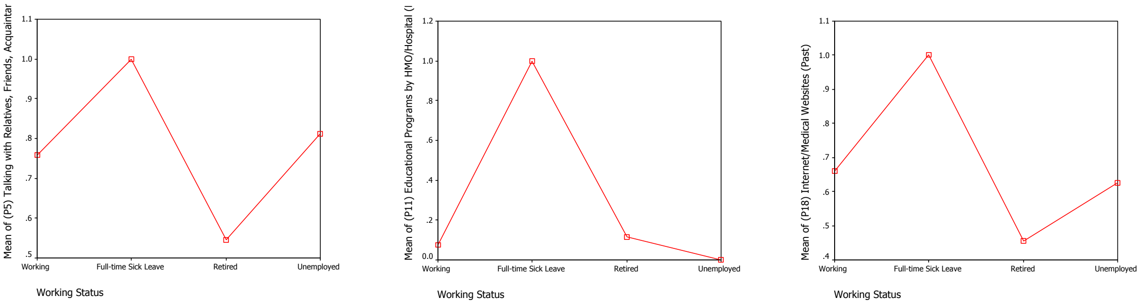


Figure 74: Companion Means Plots for Future Sources Use (1=Yes, 0=No) by Working Status

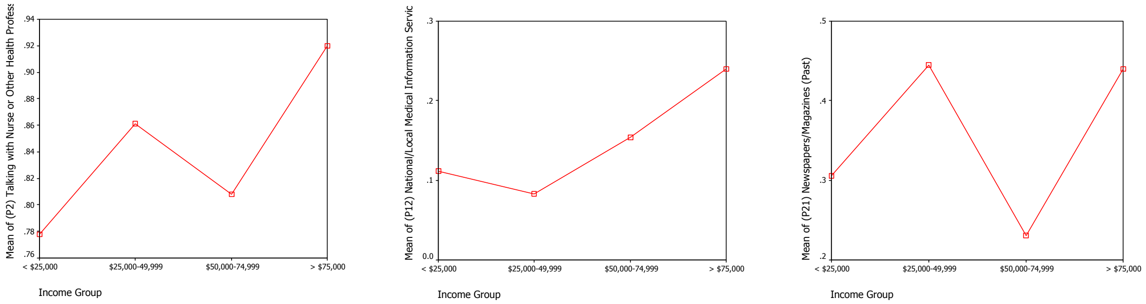


Figure 75: Companion Means Plots for Future Sources Use (1=Yes, 0=No) by Household Income (Group)

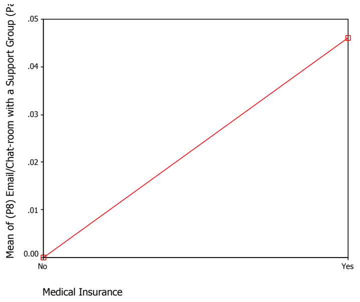


Figure 76: Companion Means Plots for Future Sources Use (1=Yes, 0=No) by Insurance

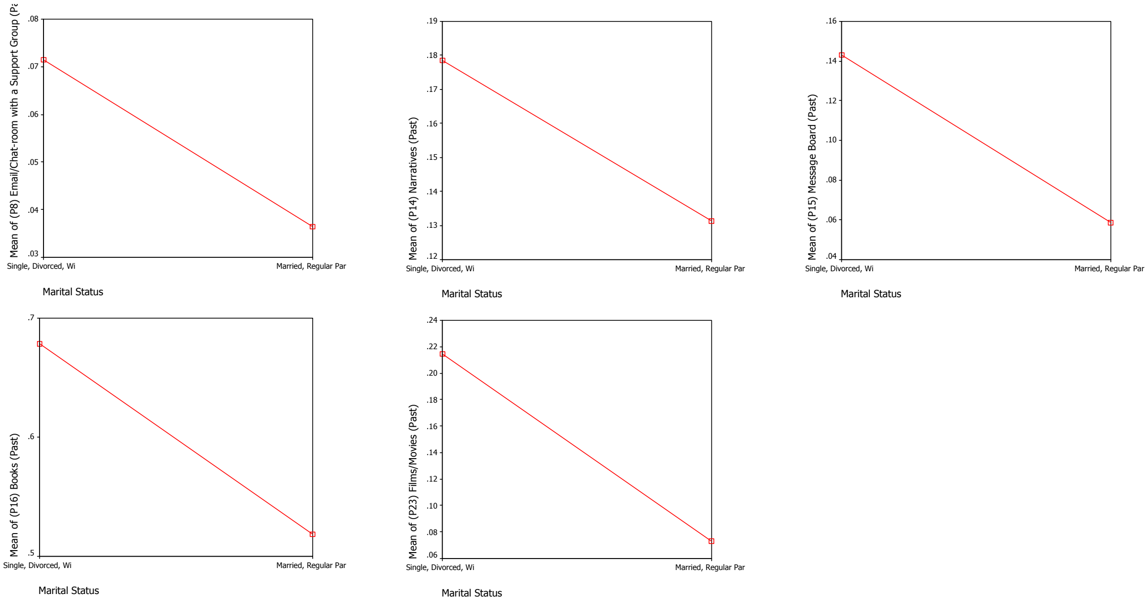


Figure 77: Companion Means Plots for Future Sources Use (1=Yes, 0=No) by Marital Status

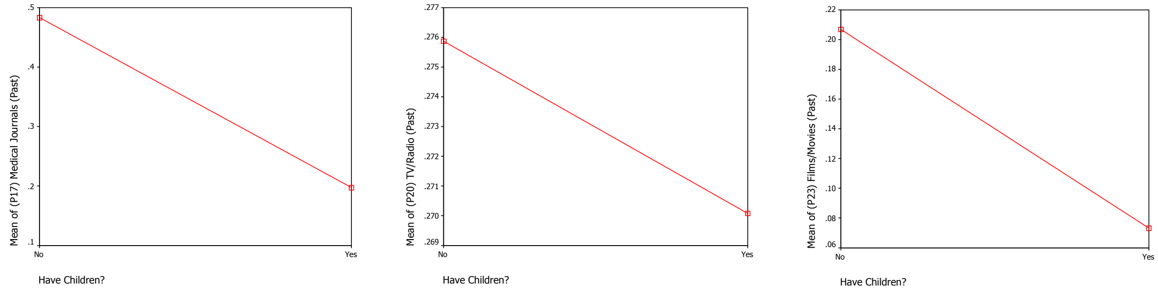


Figure 78: Companion Means Plots for Future Sources Use (1=Yes, 0=No) by Having Children Or Not

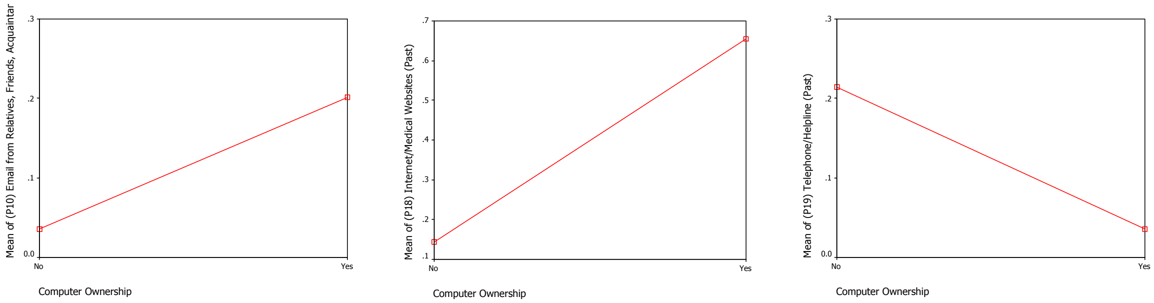


Figure 79: Companion Means Plots for Future Sources Use (1=Yes, 0=No) by Computer Ownership

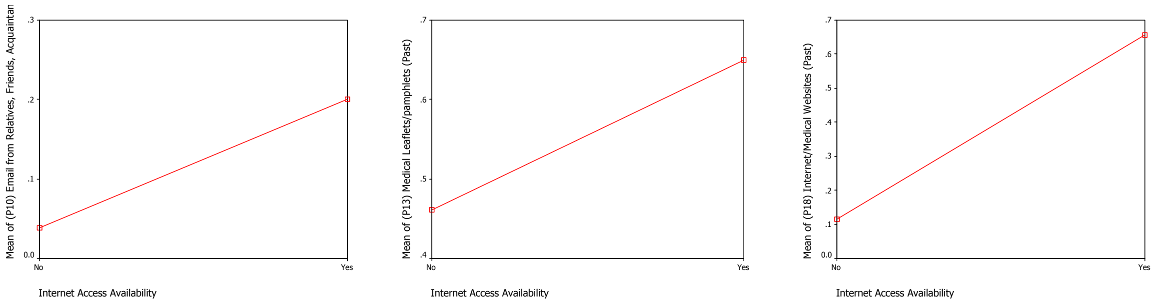


Figure 80: Companion Means Plots for Future Sources Use (1=Yes, 0=No) by Internet Access Availability

Hypothesis 5

The fifth hypothesis proposed that whether cancer patients (H5P) and their companions (H5C) will continue to use the same sources for more medical information in the future is in direct proportion to their judgments of the information quality of those sources.

Before testing the hypothesis, it is helpful to first look at the quality evaluations by patients and companions in the past and future (See Table 33-35). The results show that, although less patients and companions will go to the same sources in the future, their expectations for the information quality of those sources generally raise. It suggests that cancer patients and companions who evaluated a source as of high quality probably go to the same source again in the future.

To show the frequency counts of the future potential uses falling into each past quality evaluation category, General Loglinear Analysis was run (See Table 46). Since one didn't evaluate a source that he or she didn't go, we filtered those cases from this test. The results show that, generally the higher the information quality evaluated for a source, the higher percentage of patients and companions will use that source in the future. More detailedly, it is statistically significant for all the sources that a higher percentage of patients and companions will use sources evaluated above average than those evaluated as average, and it is statistically significant for almost half of the sources that a higher percentage of patients and companions will use sources evaluated as average than those evaluated below average. It means, whether cancer patients and their companions will continue to use the same sources for more medical information in the future is in direct proportion to their judgments of the information quality of those sources.

Table 46: Loglinear for Future Sources (Current Information Quality Evaluation as Factor)

Current Sources	Loglinear of Future Source Yes % by Quality Levels								Yes % Differences by Quality Levels						
	N	Very Poor	Poor	Below Average	Average	Good	Very Good	Excellent	1. Below Average	2. Average	3. Above Average	Differences			
												2 from 1	Sig.	3 from 2	Sig.
1 Talking with Physician or Physician's Assistant	410	0.36%		1.09%	4.96%	15.13%	27.97%	50.48%	1.45%	4.96%	93.58%	3.51%	***.002***	88.62%	***.000***
2 Talking with Nurse or Other Health Professionals	353		0.70%	0.98%	7.16%	20.08%	31.60%	39.47%	1.68%	7.16%	91.15%	5.48%	***.000***	83.99%	***.000***
3 Talking with a Support Group	63	8.27%	3.76%	9.77%	26.32%	20.30%	9.77%	21.80%	21.80%	26.32%	51.87%	4.52%	.278	25.55%	***.002***
4 Talking with Other Patients	204	1.20%	5.06%	6.51%	23.37%	25.30%	20.00%	18.55%	12.77%	23.37%	63.85%	10.60%	***.003***	40.48%	***.000***
5 Talking with Relatives, Friends, and Acquaintances	281	2.99%	6.85%	10.37%	20.21%	25.13%	12.83%	21.62%	20.21%	20.21%	59.58%	0.00%	1.000	39.37%	***.000***
6 Email from Physician or Physician's Assistant	36	3.80%	3.80%	3.80%	11.39%	11.39%	34.18%	31.65%	11.40%	11.39%	77.22%	-0.01%	1.000	65.83%	***.000***
7 Email from Nurse or Other Health Professionals	24	5.56%		5.56%	9.26%	16.67%	27.78%	35.19%	11.12%	9.26%	79.64%	-1.86%	.417	70.38%	***.000***
8 Email or Chat-room with a Support Group	20	6.38%	6.38%	10.64%	23.40%	14.89%	19.15%	19.15%	23.40%	23.40%	53.19%	0.00%	1.000	29.79%	***.026***
9 Email or Chat-room with Other Patients	13	9.38%		15.62%	15.62%	15.63%	21.87%	21.88%	25.00%	15.62%	59.38%	-9.38%	.278	43.76%	***.011***
10 Email from Relatives, Friends, and Acquaintances	67	3.55%	10.64%	6.38%	20.57%	23.40%	16.31%	19.15%	20.57%	20.57%	58.86%	0.00%	1.000	38.29%	***.000***
11 Educational Programs by HMO or Hospital	40	3.45%	3.45%	14.94%	5.75%	21.84%	8.50%	31.03%	21.84%	5.75%	61.37%	-16.09%	***.018***	55.62%	***.000***
12 National/Local Medical Information Services	63	2.26%	2.26%	5.26%	8.27%	23.31%	24.81%	33.83%	9.78%	8.27%	81.95%	-1.51%	.382	73.68%	***.000***
13 Medical Leaflets or Pamphlets	227	1.08%	1.08%	3.69%	13.67%	25.81%	29.72%	24.95%	5.85%	13.67%	80.48%	7.82%	***.003***	66.81%	***.000***
14 Narratives	70	3.40%	3.40%	7.48%	18.37%	18.37%	30.61%	18.37%	14.28%	18.37%	67.35%	4.09%	.258	48.98%	***.000***
15 Message Board	29	4.62%	4.62%	4.62%	26.15%	10.77%	26.15%	23.08%	13.86%	26.15%	60.00%	12.29%	.121	33.85%	***.005***
16 Books	215	1.14%	2.52%	2.52%	11.21%	23.11%	32.27%	27.23%	6.18%	11.21%	82.61%	5.03%	***.032***	71.40%	***.000***
17 Medical Journals	94			1.55%	8.81%	21.24%	31.61%	36.79%	1.55%	8.81%	89.64%	7.26%	***.012***	80.83%	***.000***
18 Internet or Medical Websites	194	0.76%		1.27%	13.45%	27.66%	22.59%	34.26%	2.03%	13.45%	84.51%	11.42%	***.000***	71.06%	***.000***
19 Telephone or Helpline	30	4.48%	4.48%	4.48%	10.45%	28.36%	19.40%	28.36%	13.44%	10.45%	76.12%	-2.99%	.359	65.67%	***.000***
20 TV/Radio	114	2.98%	7.23%	12.34%	31.91%	21.70%	11.49%	12.34%	22.55%	31.91%	45.53%	9.36%	.056	13.62%	***.017***
21 Newspapers /Magazines	158	2.79%	2.17%	8.98%	25.70%	30.03%	17.03%	13,31%	13.94%	25.70%	47.06%	11.76%	***.004***	21.36%	***.000***
22 Audio/Video Tapes	38	3.61%	3.61%	3.61%	25.30%	18.07%	15.66%	30.12%	10.83%	25.30%	63.85%	14.47%	.051	38.55%	***.000***
23 Films/Movies	42	3.30%	3.30%	12.09%	14.29%	23.08%	16.48%	27.47%	18.69%	14.29%	67.03%	-4.40%	.295	52.74%	***.000***

Again, the above test is based on regarding patients and companions as a whole group, we don't know whether is any significant difference between paired patients and companions. Therefore, Paired Samples T-test was run for each pair of patient and companion for both current and future (See Table 47). The results show that except that more patients than companions talked with other patients in the past (See Table 29-30), there is no big difference between patients and companions in information quality evaluation.

Table 47: Paired Samples T-test for Information Quality (Patient vs. Companion)

Sources	Patient vs. Companion (Paired)			
	Current		Future	
	N	Sig. (2-tailed)	N	Sig. (2-tailed)
1 Talking with Physician or Physician's Assistant	156	.262	122	.671
2 Talking with Nurse or Other Health Professionals	122	.521	90	.547
3 Talking with a Support Group	6	.788	5	.374
4 Talking with Other Patients	48	***.049***	32	.720
5 Talking with Relatives, Friends, and Acquaintances	85	.863	55	.244
6 Email from Physician or Physician's Assistant	5	.477	4	.391
7 Email from Nurse or Other Health Professionals	4	.718	3	.742
8 Email or Chat-room with a Support Group	3	.529	3	1.000
9 Email or Chat-room with Other Patients	2	.205	2	.205
10 Email from Relatives, Friends, and Acquaintances	8	.502	7	.370
11 Educational Programs by HMO or Hospital	4	.638	4	.624
12 National/Local Medical Information Services	7	.356	4	.391
13 Medical Leaflets or Pamphlets	58	.549	38	.491
14 Narratives	8	.476	8	.626
15 Message Board	5	.208	5	.778
16 Books	52	.118	32	.281
17 Medical Journals	8	.668	7	.846
18 Internet or Medical Websites	38	.606	31	1.000
19 Telephone or Helpline	2	*	1	*
20 TV/Radio	19	.895	14	.230
21 Newspapers /Magazines	26	.203	16	.333
22 Audio/Video Tapes	3	.840	2	1.000
23 Films/Movies	3	.423	2	.500

* The t cannot be computed because the standard error of the difference is 0.

CHAPTER VI

DISCUSSIONS AND CONCLUSIONS

Today, increasingly acting as independent learners, patients are facing a wider range of information resources, including patients with cancer (National Cancer Alliance, 1996). Cancer patients use various sources of health information to gain knowledge about their illness and prognosis, treatment options and side effects, ways to prevent recurrence, and psychological resources for coping (Cassileth et al, 1980; Fallowfield et al, 1994). So do their companions (Basch et al, 2004). The ability to clearly determine patients' and their companions' potential medical information sources can help both physicians and patients to make better communications and more efficient decisions together (Dranove, 1988; Labelle et al 1994; Kleffens et al 2003; Basch et al, 2004). However, despite the extensive literature on information provision for patients with cancer, there are a limited number of studies that have investigated the preferred sources of information for cancer patients (Mills and Davidson, 2002).

The objectives of this survey are identifications of patients' and companions' medical information sources, their evaluations of medical information quality, and their opinions about medical information benefits. The results of the study contribute to understanding patients' and companions' information needs and their uses of various medical information sources. Several conclusions are made from the data from this study.

First, over 95% of both patients and companions agreed that information increases their involvement in decision making, raises their satisfaction with treatment choices, improves their abilities to cope with cancer, and smoothes the communication among family members, which is consistent with previous studies of medical information benefits (Jefford and Tattersall, 2002; Luker et al, 1995; Cawley et al, 1990; Rutten et al, 2004; and Mills and Sullivan, 1999; Cassileth, 1980; Fallowfield et al, 1995; Coulter, 1995; Ford et al, 1995; Meredith et al, 1996). However, patients or companions seemed to less agree that information actually reduces their anxiety or mood disturbances ($P = .000$), which reaches a different conclusion from the previous studies that information can help to reduce anxiety and alleviate the uncertainty, fear, and loss invoked by cancer (Rainey, 1985; Mills and Sullivan, 1999; Fallowfield et al, 1990; Houts et al, 1991; Meredith et al, 1996; Butow et al, 1994; Rutten et al, 2004). Although the actual reasons patients and companions may have for not thinking information helpful in reducing anxiety cannot be discovered without asking them further questions about it, one possible reason is that patients and companions feel emotionally disturbed all the time during the disease, either with much or little information. Actually, when they know less about the disease, they are anxious because of having not enough information to answer their questions, which is a “not knowing” anxiety; however, when they learn more, they unavoidably learn more gloomy parts than before, which might cause a “knowing too much” anxiety.

Second, the survey found that although all the responders have been searching information about cancer since diagnoses, over 85% of them will continue to search for cancer related information in the future, which is consistent with previous studies stating that cancer patients want to become more informed about their illnesses and prefer to receive as much information as possible (Satterlund et al, 2003; Butow et al, 1997; Fallowfield et al, 1994; Hinds and Mood, 1995; Meredith et al, 1996). The survey also found that the most frequently sought topics in the past are diagnosis and treatment, drugs and side effects, and coping with cancer, with patients caring more about complementary and alternative medicine and companions caring more about cancer literature and genetics service, which is consistent with Rutten et al's (2004) study which ranked cancer-specific information (including specific diagnosis information) and treatment-related information (including side effects and alternative or complimentary treatments) as the top two information needs for cancer patients. It is also consistent with previous studies stating that persons involved in cancer wanted information about what would happen to them in the immediate future (Harris, 1998), such as disease management, prognosis, and therapeutic alternatives (Cassileth et al, 1980; Champman and Rush, 2003; Coulter, 2003; Hardwick and Lawson, 1995; Manfredi et al, 1993; Basch et al, 2004). Neither patients nor companions seem to care much about patient experiences, support groups, or financial information, which is again consistent with Rutten et al's (2004) study.

Third, the survey found that there is some but not strong relationship between cancer stages and medical topics searched by patients and companions. Both patients and companions searched for information about diagnosis, treatment (P = .027) and cancer hospitals (P = .028) more frequently in follow-up than in treatment receiving stage, and companions searched for information about insurance or financial assistance more frequently during treatment than in follow-up stage (P = .013). Although this does not totally agree with previous studies stating that patients vary in how much information they want during different stages (Leydon et al, 2000; Johnson and Meischke, 1993; Johnson, 1996), it confirms that both cancer patients and companions prefer to receive as much information as possible.

Fourth, cancer patients and companions reported their current medical information sources (ranked by frequency) as: human sources (99.3%), printed media (75.5%), networked sources (53.3%), broadcast media (30.0%), organizational sources (19.6%), and other sources (12.3%), which is consistent with the Information Source Horizon Theory for general population (Savolainen et al, 2004), except "other sources". Without asking further questions in this survey, it is hard to explain why patients and companions use or not use these sources. However, some possible explanations are provided by the Media Richness Model (Daft et al, 1987) and source strengths and weaknesses. Human sources was most frequently used probably because of their high richness (Daft et al, 1987), immediate feedback (Wilson, 1997), and emotional support (Mossman et al, 1999). Although both with low-medium richness (Daft et al, 1987), printed media was ranked second probably for the long tradition of use (Savolainen, 1995) as well as the high-literacy of the responders, and networked sources was ranked the third probably for rapid searchability (Savolainen, 1999) as well as the high-occupancy of computers and Internet accesses of the responders. Although with medium-high richness (Daft, 1987), broadcast media was ranked low perhaps for their biased information (Conesa et al, 2004) and low credibility (Hertzum et al, 2002), and organizational sources was ranked even lower possibly because that the time of a program is usually short but the interim between two programs is usually long. For example, according to some patients who participated in this survey, American Cancer Society has a one-day program early in a month but no support during the rest of that month. As for "other sources", one possible reason for its being ranked much lower by cancer patients and companions than by general population is that information source scope in the medical field might be smaller than that in the general field.

Fifth, for more detailed source types, it is not surprising that the top three most frequently used sources are all human sources. Talking with physicians or physicians' assistants (97.2%) and talking with nurses and other health professionals (83.7%) were reported as the top two medical information sources used by cancer patients and companions in the past. The quality means of these two sources are 6.22 and 6.01 respectively, which are also the highest two among all the sources. Physicians and health care providers are still the most trusted sources for cancer information than any other source, which confirms previous studies of cancer patients' information sources (Rutten et al, 2004; Mills and Davidson, 2002; Kakai et al, 1999; O'Malley et al, 1999; Pennbridge et al, 1999; Cohn et al, 2003). While it is interesting that although talking with relatives, friends, and acquaintances has a quality mean of 4.84 which is one of the lowest among all the sources, it was ranked as the third frequently used source (66.7%) by both patients and companions, which supports some of previous studies (Mills and Davidson, 2002; Carlsson, 2000) but disagrees with others (O'Malley et al, 1999; Basch et al, 2004; Cohn et al, 2003). Following these top three sources are medical leaflets or pamphlets (54.7%, quality mean 5.53) and books (51.7%, quality mean 5.61), both printed media. Such a high ranking of printed media supports most of the previous studies (Mills and Davidson, 2002; James et al, 1999; Kakai et al, 2003; Carlsson, 2000; O'Malley et al, 1999; Pautler et al, 2000; Rutten et al, 2004).

It is not surprising that TV/radio, films, audio/video tapes, and telephone/helpline are used much less frequently compared with human sources and printed media. While it is surprising that although using the Internet as a medical information source has drawn more and more attention during the past several years, and even though most of the responders who participated in this survey own computers and the Internet accesses, the Internet/Medical websites was only ranked the seventh, which is not as high as it was expected to be. Actually, the percentage of using the Internet by cancer patients and companions is not low (46.2%), which is consistent with previous studies reporting that 42~49% of patients used the Internet as a major means of gathering information about cancer (Fogel et al, 2002; Satterlund et al, 2003). However, regardless of its percentage of use, it is ranked behind human sources and printed media. This means that although the Internet was used by cancer patients and companions for medical information more often than before when studies found that only a small percent of patients (less than 7~10%) reported using the Internet (Diefenbach et al, 2002; Mills and Davidson, 2002; Raupach and Hiller, 2002), it was still used much less often than human sources or printed media. More surprisingly, with studies stating that about a third (30%) of email users, or about 32 million Americans, have exchanged health-related email with friends, family members, and doctors (Fox and Fallows, 2003), not many patients and companions reported using emails with relatives, friends, acquaintances (16.0%), and physicians (9.0%), and even less reported using emails or chat-rooms with nurses, support groups (4.7%), or other patients (3.1%), although most of them own computers and have the Internet accesses.

There are many possible reasons for patients and companions not using the Internet or email often. Since most patients and companions in this survey have computers and the Internet accesses, reasons such as requirements of computer or Internet accesses (Savolainen, 1999) and digital division (Murray et al, 2003) can be screened out for the present study. Other possible reasons include the unknown credibility of the Internet (Jefford and Tattersall, 2002; Hoffman-Goetz and Clarke, 2000; Silberg et al, 1997) and its lack of in-person assessment and nonverbal clues (Fox and Fallows, 2003).

Sixth, comparing patients with their paired companions, we found that they are quite similar in using medical information sources either for current or in the future, which supports Basch et al's (2004) conclusion that there was a high rate of concordance between patient' and companion' information seeking behavior. However, there are still some differences between them. Companions seemed to use medical leaflets or pamphlets ($P = .009$) more than patients in the past. One possible reason is that companions usually spend much more time waiting in the clinic than patients who have to see physicians or receive treatment. Companions also used emails from physician or physician's assistant ($P = .004$) more than patients. One possible reason for this is that companions might need to know something that they do not want patients to know. Another possible reason is that companions in the survey are younger than patients, so they are more used to email than patients. Moreover, Companions used and will use the Internet or medical websites (*P* = .000) more than patients both for current and in the future. Again, it might because companions for this study are younger, compared with patients. It is might also because that most companions are still working but the majority of the patients are not, since Internet accesses are more common in working places.

Seventh, comparing current sources with future sources, the results showed that only the percentage of email being cited as a future source goes up, which might suggest a brighter future for using emails as a cancer information source than present. With the exception of this and for the majority of the 23 sources listed in the survey, a commonly lower percentage of patients and companions would use the same sources in the future, especially for those traditional sources including talking with physician or physician's assistant (*P* = .000), talking with nurse or other health professionals (*P* = .000), talking with other patients (*P* = .003), talking with relatives, friends, and acquaintances (*P* = .000), medical leaflets or pamphlets (*P* = .000), books (*P* = .001), and newspapers/magazines (*P* = .003). So do some newer sources including the Internet and medical websites (*P* = .031). Nevertheless, in spite of the lower percentage of potential future use, patients' and companions' expectations for the information quality of those sources are higher than current quality evaluations. For example, Paired Samples T-tests showed that the expected quality levels of talking with physician or physician's assistant, talking with nurse or other health professionals, email from relatives, friends, and acquaintances, and medical leaflets or pamphlets are all significantly higher than current quality evaluations (*P* = .000). It might suggest that cancer patients and companions who evaluated these sources high-quality probably will go to the same source again in the future, while those who evaluated these sources low-quality probably will not go to the same source again. It might also suggest that people are usually wearing rose-colored glasses for future.

Eighth, patients and companions also reported which specific websites they visited in the past and will visit in the future. There was a very interesting finding that search engines such as Google and Yahoo were listed as the third popular websites for cancer information, following National Cancer Institute and American Cancer Society. National Institute of Health, WebMD, and WebDoctor were listed within 10 but behind search engines. It is possible that for those well-known websites, patients and companions visited or will visit the website address directly, but since they don't know more addresses, they used or will use search engines for the cancer information they would like to know by key words. One implication here might be that the rankings for those not so well known medical websites on search engines thus becomes important, which probably decides where patients and companions will go to since people usually click those shown on the first page of the searching results.

Ninth, demographics including gender, age, education, working status, household income, computer ownership, and Internet access availability appear to have greater influence than other demographics on both cancer patients' and companions' current medical information sources: 1) Females used more varied medical information sources than males in the past ($P = .006$), and used more printed ($P = .000$) and broadcast media also ($P = .003$). 2) Patients and companions who are younger used more varied medical information sources than those who are older ($P = .002$), and used networked sources such as the Internet more often also ($P = .000$). 3) The higher education a patient or companion has, the more varied sources he or she used ($P = .000$). A higher education degree also comes together with a higher usage of networked ($P = .000$), printed ($P = .000$) and organization sources (*P* = .000). 4) Patients and companions who are retired used much less varied information sources than those who are either still working, in full-time sick leave, or unemployed (*P* = .003). The retired used much less networked (*P* = .000) or printed (*P* = .000) media than others too. 5) Patients and companions with household income over $25,000 used more varied information sources than those whose income are less than $25,000 (*P* = .007), and they used networked (*P* = .000), organizational (*P* = .001) and broadcast (*P* = .013) media more often also. 6) Patients and companions who own computers and have the Internet accesses definitely used networked sources more than those who do not (*P* = .000 for both). But interestingly, they also used printed media (*P* = .026 and .002 respectively) and attended organizational programs (*P* = .011 and .006) more often.

Tenth, demographics including gender, age, education, working status, household income, computer ownership, and Internet access availability appear to have greater predicting power than other demographics on both cancer patients' and companions' future medical information sources: 1) Females will continue to use more varied medical information sources than males in the future (*P* = .001), and use more printed (*P* = .011) and broadcast media than males (*P* = .014) also. 2) People who are younger will continue to use more varied medical information sources than those who are older (*P* = .007), and use networked sources more often (*P* = .000). 3) The higher education degree a patient or companion has, the more varied sources he or she will use in the future (*P* = .000). A higher education degree also implies a higher probability of using human (*P* = .022), networked (*P* = .000), printed (*P* = .000) and organization sources (*P* = .000) in the future. 4) Patients and companions who are retired will probably use much less varied information sources than those who are either still working, in full-time sick leave, or unemployed (*P* = .028). The retired will probably use much less networked (*P* = .000) media than others in the future. 5)

Patients and companions with household income over \$25,000 will probably use more varied information sources than those whose income are less than \$25,000 (*P* = .007) in the future, and they will use networked (*P* = .001), organizational (*P* = .004) and broadcast (*P* = .017) media more often also. 6) Patients and companions who own computers and have the Internet accesses will definitely use networked sources more than those who do not (*P* = .000 for both). Interestingly again, they will also use printed media (*P* = .008 and .000 respectively) and attended organizational programs (*P* = .009 and .002) more often.

Eleventh, the study also found that whether cancer patients and their companions will continue to use the same sources for more medical information in the future is in direct proportion to their judgments of the information quality of those sources. The results showed that the higher the information quality evaluated for a source, the higher percentage of patients and companions will use that source in the future. It confirms previous studies stating that judgments drawn from the previous experiences have an impact on the future use of information sources (Hertzum et al, 2002). Therefore, in addition to demographic characteristics, knowing how cancer patients and companions think about current medical information sources will be very helpful to predict which information sources they will go to in the future.

Last but not the least, although there are significant differences between patients and companions in gender, age (group), working status, medical insurance, marital status, computer ownership, and Internet accesses, their information seeking behaviors seemed highly concordant for most of the hypotheses tests, including opinions about information benefits, topics by stage, information source horizon, and information quality evaluations. However, sometimes they behave differently with each other during information seeking processes. For example, the cancer related topics they search for are slightly different (patients usually searched for diagnosis and treatment while the companions searched for coping with cancer in the past, and companions will search for topics including coping with cancer, drugs and side effects, cancer prevention/genetics/causes, and insurance/financial assistance in the future but patients will not). And also, companions seem to use more varied sources than patients, and they definitely use more networked sources such as the Internet ($P = .000$) also.

Another interesting finding is that patients and companions surveyed for the present study are on the whole opposite in gender between each other. Therefore, their information seeking behaviors might be influenced or explained by gender factors. By and large, the study implied a noticeable correlation for information seeking behaviors between cancer patients and their paired companions, both of whom regard health care professionals as the most trustable information source. This agrees with previous studies of health care team-patient relationship that such a relationship is a triangle and the involvement of both health care team and companions is very important for the care and treatment of cancer patients (Blanchard et al, 1996; Humphrey et al, 1992).

In summary, the present study gives a broad outline of the sources or potential sources used by patients and companions in the past and in the future (See Table 48). It contributes to understanding *who* searches for information, *why* they search for information (*importance*), *what* they need to know (*topics*), *when* during the course of care (*stage*), *where* they receive information (*source*), and how they evaluate the *information quality* from these sources. It also helps to clarify the relationship between socio-demographic (*predictor*) and medical information searching, and the relationship between judgments drawn from the previous experiences and the future use of information sources.

Table 48: Study Findings Summary

	Top 5 in Ranked Order			
Who	Patient		Companion	
Why (Benefits)	1. Increase involvement in decision making 2. Improve ability to cope with cancer 3. Increase satisfaction with treatment choices 4. Improve communication among family members		1. Increase involvement in decision making 2. Improve ability to cope with cancer 3. Improve communication among family members 4. Increase satisfaction with treatment choices	
When	Current	Future	Current	Future
What (Topics)	1. Diagnosis and Treatment 2. Drugs and Side Effects 3. Coping with Cancer 4. Nutrition 5. Cancer Literature	1. Diagnosis and Treatment 2. Drugs and Side Effects 3. Coping with Cancer 4. Nutrition 5. Cancer Literature	1. Diagnosis and Treatment 2. Drugs and Side Effects 3. Coping with Cancer 4. Cancer Literature 5. Nutrition	1. Diagnosis and Treatment 2. Drugs and Side Effects 3. Coping with Cancer 4. Cancer Literature 5. Nutrition
Where (Source Type)	1. Human 2. Printed Media 3. Networked Sources 4. Broadcast Media 5. Organizational Sources	1. Human 2. Printed Media 3. Networked Sources 4. Broadcast Media 5. Organizational Sources	1. Human 2. Printed Media 3. Networked Sources 4. Broadcast Media 5. Organizational Sources	1. Human 2. Printed Media 3. Networked Sources 4. Broadcast Media 5. Organizational Sources
Where (Specific Sources)	1. Talking with Physician or Physican's Assistant 2. Talking with Nurse or Other Health Professionals 3. Talking with Relatives, Friends, and Acquaintances 4. Talking with Other Patients 5. Medical Leaflets or Pamphlets	1. Talking with Physician or Physican's Assistant 2. Talking with Nurse or Other Health Professionals 3. Talking with Relatives, Friends, and Acquaintances 4. Talking with Other Patients 5. Books	1. Talking with Physician or Physican's Assistant 2. Talking with Nurse or Other Health Professionals 3. Talking with Relatives, Friends, and Acquaintances 4. Medical Leaflets or Pamphlets 5. Internet or Medical Websites	1. Talking with Physician or Physican's Assistant 2. Talking with Nurse or Other Health Professionals 3. Internet or Medical Websites 4. Talking with Relatives, Friends, and Acquaintances 5. Medical Leaflets or Pamphlets
Quality Evaluation	1. Talking with Physician or Physican's Assistant 2. Talking with Nurse or Other Health Professionals 3. Medical Journals 4. Internet or Medical Websites 5. Email from Physician or Physician's Assistant	1. Email or Chat-room with Other Patients 2. Talking with Physician or Physican's Assistant 3. Talking with Nurse or Other Health Professionals 4. Films/Movies 5. Message Board	1. Email from Nurse or Other Health Professionals 2. Medical Journals 3. Talking with Physician or Physican's Assistant 4. National/Local Medical Information Services 5. Talking with Nurse or Other Health Professionals	1. Medical Journals 2. Email from Nurse or Other Health Professionals 3. Talking with Physician or Physican's Assistant 4. Telephone/Helpline 5. Talking with Nurse or Other Health Professionals
Predictors	Education, Household Income, Gender, Age, Working Status			

Of course, the present study has several limitations. Patients interviewed in this study were mainly collected from the Ingram Cancer Center at Vanderbilt University, which is located in Nashville, Tennessee. It is suggested that future studies address cancer populations from different areas of the country. Also, evaluating other cancer populations within the US, different types of cancer population, and minority cancer patients would contribute to further knowledge in this field. Eight cancer groups were used for this study, however, the group called "Other", which contained patients with cancer such as melanoma and brain cancer did not have sufficient patients of one type of cancer for statistically significant analyses. Thus, future studies of patients' and companion's cancer information sources could be designed for these groups. Moreover, since we didn't ask further questions about why patients and companions believe information can or cannot bring certain benefits, so we do not know the actual reasons for their not thinking information helpful in reducing anxiety, which need to be clarified in future studies. Other more detailed studies such as the connections between topics and specific sources, and why certain sources are not used as frequently by specific groups also merit future investigation. Finally, since our survey involved cancer patients and their companions only, we do not know how oncologists, an indispensable party in the health care team-patient triangle, think about what information patients and companions need and where they went, will go, and should go for these information in the current and for future. Therefore, future research involving physicians' views is needed to make the information source study of this triangle more complete.

APPENDIX A: QUESTIONNAIRE VERSION 1

Medical Information Sources Inquiry for Cancer Patients

The objective of this survey is to investigate the medical information sources you've visited and will visit, and the quality of the medical information you think or you expect from those sources.

Part A: Background Information

All information will be kept confidential.

(Please check one box per question)

1	☐ **I am waiting to see the Doctor**	☐ **I have seen the Doctor**
2	☐ **I am currently receiving treatment**	☐ **I am in follow-up**
3	**What type of cancer did or do you have?** ☐ Bladder cancer ☐ Breast cancer ☐ Colon cancer ☐ Endometrial cancer ☐ Head and Neck cancer ☐ Leukemia	☐ Lung cancer ☐ Melanoma ☐ Non-Hodgkin's lymphoma ☐ Ovarian Cancer ☐ Prostate cancer ☐ Rectal cancer ☐ *Other:* __________________
4	**What is your gender?** ☐ Male	☐ Female
6	**What is your age (in years)?** _________	
5	**How would you describe your racial group?** ☐ White (Non Hispanic) ☐ African American ☐ Asian/Pacific Islander	☐ Hispanic or Latin Origin ☐ Bi-racial ☐ *Other:* __________________
7	**What is the highest degree completed by you (the patient)?** ☐ Elementary: 0-8 years ☐ Some High School (no diploma) ☐ High School (With diploma)	☐ Some College ☐ Bachelors degree ☐ Graduate/Professional
8	**What is your working status?** ☐ Working ☐ Full-time sick leave	☐ Retired ☐ Unemployed
9	**Which of the following categories best describes your household income?** ☐ Under $5,000 ☐ $5,000 – $9,999 ☐ $10,000 – $14,999 ☐ $15,000 – $19,999 ☐ $20,000 – $24,999	☐ $25,000 – $34,999 ☐ $35,000 – $49,999 ☐ $50,000 – $74,999 ☐ $75,000 and above
10	**What is your marital status?** ☐ Married/regular partnership	☐ Single/divorced, widowed
11	**Do you have children?** ☐ Yes	☐ No

Part B: Medical Information Sources

All information will be kept confidential.

In this part, please pick out all the information sources that you <u>WENT</u> to for medical information, and evaluate the quality of information you got from those sources.

<u>Example</u>: If you ***<u>WENT</u>*** to TV but not Radio for medical information, and you think that the quality of information from TV is 4, your answer should be:

Medical Information Sources		*<u>Did</u>* you go here for information?		If "Yes", how good is the quality of information?
				Low →→→ High
20	TV	☐Yes	☐ No	1 2 3 4 5 6 7
21	Radio	☐Yes	☐ No	1 2 3 4 5 6 7

(Please check all that apply and circle the appropriate number)

Medical Information Sources		***<u>Did</u>* you go here for medical information?**		**If "Yes", how good is the quality of information?**						
				Low			**→→→**			**High**
1	Talking with Physician / Nurse / Healthcare Provider	☐ Yes	☐ No	1	2	3	4	5	6	7
2	Talking with Other Health Professional / Consultant	☐ Yes	☐ No	1	2	3	4	5	6	7
3	Attending Educational Program by HMO / Hospital	☐ Yes	☐ No	1	2	3	4	5	6	7
4	National/Local Information Services (IS)	☐ Yes	☐ No	1	2	3	4	5	6	7
5	E-mails from Health Professional / HMO / IS	☐ Yes	☐ No	1	2	3	4	5	6	7
6	Talking with Support Group	☐ Yes	☐ No	1	2	3	4	5	6	7
7	E-mails from Support Group	☐ Yes	☐ No	1	2	3	4	5	6	7
8	Talking with Other Patients	☐ Yes	☐ No	1	2	3	4	5	6	7
9	E-mails from Other Patients	☐ Yes	☐ No	1	2	3	4	5	6	7
10	Narratives (Written Stories by Other Patients)	☐ Yes	☐ No	1	2	3	4	5	6	7
11	Talking with Relatives / Friends / Acquaintances	☐ Yes	☐ No	1	2	3	4	5	6	7
12	E-mails from Relatives / Friends / Acquaintances	☐ Yes	☐ No	1	2	3	4	5	6	7
13	Leaflets / Pamphlets	☐ Yes	☐ No	1	2	3	4	5	6	7
14	Medical Journals / Medline / PubMed	☐ Yes	☐ No	1	2	3	4	5	6	7
15	Books	☐ Yes	☐ No	1	2	3	4	5	6	7
16	Newspapers	☐ Yes	☐ No	1	2	3	4	5	6	7
17	Magazines	☐ Yes	☐ No	1	2	3	4	5	6	7
18	Internet	☐ Yes	☐ No	1	2	3	4	5	6	7
19	Telephone / Helpline	☐ Yes	☐ No	1	2	3	4	5	6	7
20	TV	☐ Yes	☐ No	1	2	3	4	5	6	7
21	Radio	☐ Yes	☐ No	1	2	3	4	5	6	7
22	Audio / Video Tapes	☐ Yes	☐ No	1	2	3	4	5	6	7
23	Films	☐ Yes	☐ No	1	2	3	4	5	6	7

APPENDIX B: QUESTIONNAIRE VERSION 2

Medical Information Sources Inquiry for Cancer Patients

The objective of this survey is to investigate the medical information sources you've visited and will visit, and the quality of the medical information you think or you expect from those sources.

Part A: Background Information

All information will be kept confidential.

(Please check one box per question)

1	☐ **I am waiting to see the Doctor**	☐ **I have seen the Doctor**
2	☐ **I am currently receiving treatment**	☐ **I am in follow-up**
3	**What type of cancer did or do you have?** ☐ Bladder cancer ☐ Breast cancer ☐ Colon cancer ☐ Endometrial cancer ☐ Head and Neck cancer ☐ Leukemia	☐ Lung cancer ☐ Melanoma ☐ Non-Hodgkin's lymphoma ☐ Ovarian Cancer ☐ Prostate cancer ☐ Rectal cancer ☐ *Other:* ______________________
4	**What is your gender?** ☐ Male	☐ Female
6	**What is your age (in years)?** ___________	
5	**How would you describe your racial group?** ☐ White (Non Hispanic) ☐ African American ☐ Asian/Pacific Islander	☐ Hispanic or Latin Origin ☐ Bi-racial ☐ *Other:* ______________________
7	**What is the highest degree completed by you (the patient)?** ☐ Elementary: 0-8 years ☐ Some High School (no diploma) ☐ High School (With diploma)	☐ Some College ☐ Bachelors degree ☐ Graduate/Professional
8	**What is your working status?** ☐ Working ☐ Full-time sick leave	☐ Retired ☐ Unemployed
9	**Which of the following categories best describes your household income?** ☐ Under $5,000 ☐ $5,000 – $9,999 ☐ $10,000 – $14,999 ☐ $15,000 – $19,999 ☐ $20,000 – $24,999	☐ $25,000 – $34,999 ☐ $35,000 – $49,999 ☐ $50,000 – $74,999 ☐ $75,000 and above
10	**What is your marital status?** ☐ Married/regular partnership	☐ Single/divorced, widowed
11	**Do you have children?** ☐ Yes	☐ No

Part B: Medical Information Sources

All information will be kept confidential.

In this part, please pick out all the information sources where you <u>FIND</u> medical information, and evaluate the quality of information that you received from those sources.

<u>Example</u>: If you ***<u>FIND</u>*** medical information on TV but not on the Radio information, and you think that the information from TV is not very good, your answer should be:

Medical Information Sources		*<u>Did</u>* you go here for information?		If "Yes", how good is the quality of information?
				Poor → Excellent
20	TV	☐Yes	☐ No	1 2 3 4 5 6 7
21	Radio	☐Yes	☐ No	1 2 3 4 5 6 7

(Please check all that apply and circle the appropriate number)

Medical Information Sources		***<u>Did</u>* you go here for medical information?**		**If "Yes", how good is the quality of information?**
				Poor → Excellent
1	Talking with Your Physician or Physician's Assistant	☐ Yes	☐ No	1 2 3 4 5 6 7
2	Talking with your physician's nurse or other health professional in their office	☐ Yes	☐ No	1 2 3 4 5 6 7
3	Talking with Other Health Professional / Consultant	☐ Yes	☐ No	1 2 3 4 5 6 7
4	Attending Educational Program by HMO / Hospital	☐ Yes	☐ No	1 2 3 4 5 6 7
5	National/Local Medical Information Services (such as the National Institute of Health or the National Cancer Institute)	☐ Yes	☐ No	1 2 3 4 5 6 7
6	E-mail from Physician	☐ Yes	☐ No	1 2 3 4 5 6 7
7	E-mail from Physician's Nurse	☐ Yes	☐ No	1 2 3 4 5 6 7
8	Talking with a Support Group	☐ Yes	☐ No	1 2 3 4 5 6 7
9	E-mails from a Support Group	☐ Yes	☐ No	1 2 3 4 5 6 7
10	Talking with Other Patients	☐ Yes	☐ No	1 2 3 4 5 6 7
11	E-mails from Other Patients	☐ Yes	☐ No	1 2 3 4 5 6 7
12	Narratives (Written Stories by Other Patients)	☐ Yes	☐ No	1 2 3 4 5 6 7
13	Talking with Relatives / Friends / Acquaintances	☐ Yes	☐ No	1 2 3 4 5 6 7
14	E-mails from Relatives / Friends / Acquaintances	☐ Yes	☐ No	1 2 3 4 5 6 7
15	Medical Leaflets / Pamphlets	☐ Yes	☐ No	1 2 3 4 5 6 7
16	Medical Journals / Medline / PubMed	☐ Yes	☐ No	1 2 3 4 5 6 7
17	Books	☐ Yes	☐ No	1 2 3 4 5 6 7
18	Internet Medical Web Sites	☐ Yes	☐ No	1 2 3 4 5 6 7
19	Telephone / Helpline	☐ Yes	☐ No	1 2 3 4 5 6 7
20	TV / Radio	☐ Yes	☐ No	1 2 3 4 5 6 7
21	Newspapers / Magazines	☐ Yes	☐ No	1 2 3 4 5 6 7
22	Audio / Video Tapes	☐ Yes	☐ No	1 2 3 4 5 6 7
23	Films / Movies	☐ Yes	☐ No	1 2 3 4 5 6 7

Part C: Medical Information Searching

All information will be kept confidential.

In this part, please pick out all the information sources that you WILL go to when you are searching for more medical information, and estimate the quality of the information you expect to find.

Example: If you ***WILL*** go to Internet but not to Books when you are searching for more medical information, and you expect the quality of information from Internet to be high, your answer should be:

Medical Information Sources		*Would* you go here for information?		If "Yes", how good do you expect the information to be?
				Poor → Excellent
15	Internet	☐Yes	☐ No	1 2 3 4 5 6 7
18	Books	☐Yes	☐ No	1 2 3 4 5 6 7

(Please check all that apply and circle the appropriate number)

Medical Information Sources		***Will* you go here for more medical information?**		**If "Yes", how good do you expect the information to be?**
				Poor → Excellent
1	Talking with Your Physician or Physician's Assistant	☐ Yes	☐ No	1 2 3 4 5 6 7
2	Talking with your physician's nurse or other health professional in their office	☐ Yes	☐ No	1 2 3 4 5 6 7
3	Talking with Other Health Professional / Consultant	☐ Yes	☐ No	1 2 3 4 5 6 7
4	Attending Educational Program by HMO / Hospital	☐ Yes	☐ No	1 2 3 4 5 6 7
5	National/Local Medical Information Services (such as the National Institute of Health or the National Cancer Institute)	☐ Yes	☐ No	1 2 3 4 5 6 7
6	E-mail from Physician	☐ Yes	☐ No	1 2 3 4 5 6 7
7	E-mail from Physician's Nurse	☐ Yes	☐ No	1 2 3 4 5 6 7
8	Talking with a Support Group	☐ Yes	☐ No	1 2 3 4 5 6 7
9	E-mails from a Support Group	☐ Yes	☐ No	1 2 3 4 5 6 7
10	Talking with Other Patients	☐ Yes	☐ No	1 2 3 4 5 6 7
11	E-mails from Other Patients	☐ Yes	☐ No	1 2 3 4 5 6 7
12	Narratives (Written Stories by Other Patients)	☐ Yes	☐ No	1 2 3 4 5 6 7
13	Talking with Relatives / Friends / Acquaintances	☐ Yes	☐ No	1 2 3 4 5 6 7
14	E-mails from Relatives / Friends / Acquaintances	☐ Yes	☐ No	1 2 3 4 5 6 7
15	Medical Leaflets / Pamphlets	☐ Yes	☐ No	1 2 3 4 5 6 7
16	Medical Journals / Medline / PubMed	☐ Yes	☐ No	1 2 3 4 5 6 7
17	Books	☐ Yes	☐ No	1 2 3 4 5 6 7
18	Internet Medical Web Sites	☐ Yes	☐ No	1 2 3 4 5 6 7
19	Telephone / Helpline	☐ Yes	☐ No	1 2 3 4 5 6 7
20	TV / Radio	☐ Yes	☐ No	1 2 3 4 5 6 7
21	Newspapers / Magazines	☐ Yes	☐ No	1 2 3 4 5 6 7
22	Audio / Video Tapes	☐ Yes	☐ No	1 2 3 4 5 6 7
23	Films / Movies	☐ Yes	☐ No	1 2 3 4 5 6 7

APPENDIX C: QUESTIONNAIRE VERSION 3

Medical Information Sources Inquiry for Cancer Patients

The objective of this survey is to investigate the medical information sources you’ve visited and will visit, and the quality of the medical information you think or you expect from those sources.

Part A: Background Information All information will be kept confidential.

(Please check one box per question)

1	**☐ I am waiting to see the Doctor**		**☐ I have seen the Doctor**	
2	**☐ I am currently receiving treatment**		**☐ I am in follow-up**	
3	**What type of cancer did or do you have?** ☐ Bladder cancer ☐ Breast cancer	☐ Colon cancer ☐ Endometrial cancer ☐ Head and Neck cancer ☐ Leukemia	☐ Lung cancer ☐ Melanoma ☐ Non-Hodgkin’s lymphoma ☐ Ovarian Cancer	☐ Prostate cancer ☐ Rectal cancer ☐ *Other:* ____________
4	**What is your gender?**	☐ Male	☐ Female	
5	**What is your age (in years)?**	______________		
6	**How would you describe your racial group?**	☐ White (Non Hispanic) ☐ African American	☐ Asian/Pacific Islander ☐ Hispanic or Latin Origin	☐ Bi-racial ☐ *Other:* ____________
7	**What is the highest degree completed by you?**	☐ Elementary: 0-8 years ☐ Some High School (no diploma)	☐ High School (With diploma) ☐ Some College	☐ Bachelors degree ☐ Graduate/Professional
8	**What is your working status?**	☐ Working ق Retired	☐ Full-time sick leave	☐ Unemployed
9	**Which of the following categories best describes your income?**	☐ Under $5,000 ☐ $5,000 – $9,999 ☐ $10,000 – $14,999	☐ $15,000 – $19,999 ☐ $20,000 – $24,999 ☐ $25,000 – $34,999	☐ $35,000 – $49,999 ☐ $50,000 – $74,999 ☐ $75,000 and above
10	**What is your marital status?**	☐ Married/regular partnership	☐ Single/divorced, widowed	
11	**Do you have children?**	☐ Yes	☐ No	

Part B: Medical Information Sources

All information will be kept confidential.

In this part, please:

1) ***Pick out all the information sources where you <u>FIND</u> medical information, and evaluate the quality of information that you received from those sources;***
2) ***Pick out all the information sources that you <u>WILL</u> go to when you are searching for <u>more</u> medical information, and estimate the quality of the information you expect to find.***

<u>Example</u>: If you ***<u>FIND</u>*** medical information on Telephone / helpline but not on the TV / radio information, and you think that the information from Telephone / helpline is not very good; And in the future, you ***<u>WILL</u>*** go to Internet medical web sites but not Telephone / helpline or TV / radio when you are searching for ***<u>more</u>*** medical information, and estimate the quality of the information from Internet to be high, your answer should be:

	Medical Information Sources	***<u>Did</u>*** **you go here for medical information?**	**If "Yes", how good is the quality of information?**	***<u>Will</u>*** **you go here for more medical information?**		**If "Yes", how good do you expect the information to be?**
			Poor → Excellent			**Poor → Excellent**
17	Internet medical web sites	☐ Yes ☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
18	Telephone / helpline	☐ Yes ☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
19	TV / radio	☐ Yes ☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7

(Please check all that apply and circle the appropriate number)

	Medical Information Sources	***Did*** **you go here for medical information?**		**If "Yes", how good is the quality of information?**	***Will*** **you go here for more medical information?**		**If "Yes", how good do you expect the information to be?**
				Poor → Excellent			**Poor → Excellent**
1	Talking with your physician or physician's assistant	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
2	E-mail from your physician or physician's assistant	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
3	Talking with your physician's nurse / other health professional in their office	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
4	E-mail from physician's nurse / other health professional	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
5	Attending educational program by HMO / hospital	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
6	Talking with a support group	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
7	E-mails from a support group	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
8	Talking with other patients	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
9	E-mails from other patients	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
10	Narratives (written stories by other patients)	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
11	Talking with relatives / friends / acquaintances	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
12	E-mails from relatives / friends / acquaintances	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
13	National / local medical information services (such as the National Institute of Health or the National Cancer Institute)	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
14	Medical leaflets / pamphlets	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
15	Medical journals / Medline / PubMed	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
16	Books	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
17	Internet medical web sites	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
18	Telephone / helpline	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
19	TV / radio	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
20	Newspapers / magazines	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
21	Audio / video tapes	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
22	Films / movies	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7

APPENDIX D: QUESTIONNAIRE VERSION 4

Medical Information Sources Inquiry for Cancer Patients

The objective of this survey is to investigate the medical information sources you've visited and will visit, and the quality of the medical information you think or you expect from those sources.

Part A: Background Information

All information will be kept confidential.

(Please check one box per question)

1	☐ **I am waiting to see the Doctor**	☐ **I have seen the Doctor**
2	☐ **I am currently receiving treatment**	☐ **I am in follow-up**
3	**What type of cancer did or do you have?** ☐ Bladder cancer ☐ Breast cancer ☐ Colon cancer ☐ Endometrial cancer ☐ Head and Neck cancer ☐ Leukemia	☐ Lung cancer ☐ Melanoma ☐ Non-Hodgkin's lymphoma ☐ Ovarian Cancer ☐ Prostate cancer ☐ Rectal cancer ☐ *Other:* ________________
4	**What is your gender?** ☐ Male	☐ Female
5	**What is your age (in years)?** _________	
6	**How would you describe your racial group?** ☐ White (Non Hispanic) ☐ African American ☐ Asian/Pacific Islander	☐ Hispanic or Latin Origin ☐ Bi-racial ☐ *Other:* ________________
7	**What is the highest degree completed by you (the patient)?** ☐ Elementary: 0-8 years ☐ Some High School (no diploma) ☐ High School (With diploma)	☐ Some College ☐ Bachelors degree ☐ Graduate/Professional
8	**What is your working status?** ☐ Working ☐ Full-time sick leave	☐ Retired ☐ Unemployed
9	**Which of the following categories best describes your household income?** ☐ Under $5,000 ☐ $5,000 – $9,999 ☐ $10,000 – $14,999 ☐ $15,000 – $19,999 ☐ $20,000 – $24,999	☐ $25,000 – $34,999 ☐ $35,000 – $49,999 ☐ $50,000 – $74,999 ☐ $75,000 and above

Part B: Medical Information Sources

All information will be kept confidential.

In this part, please:

1) Pick out all the information sources where you FIND medical information, and evaluate the quality of information that you received from those sources.

Example: If you ***FIND*** medical information on Internet medical web sites and Telephone / helpline but not on the TV / radio, and you think that the information from Internet medical web sites is of high quality but the information from Telephone / helpline is not very good, your answer should be:

	Medical Information Sources	*Did* you go here for medical information?		If "Yes", how good is the quality of information?	*Will* you go here for more medical information?		If "Yes", how good do you expect the information to be?
				Poor → Excellent			Poor → Excellent
17	Internet medical web sites	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
18	Telephone / helpline	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
19	TV / radio	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7

2) Pick out all the information sources that you WILL go to when you are searching for more medical information, and estimate the quality of the information you expect to find.

Example: In the future, if you ***WILL*** go to Internet medical web sites but not Telephone / helpline or TV / radio when you are searching for ***MORE*** medical information, and you estimate that the quality of the information from Internet medical web sites to be high, your answer should be:

	Medical Information Sources	*Did* you go here for medical information?		If "Yes", how good is the quality of information?	*Will* you go here for more medical information?		If "Yes", how good do you expect the information to be?
				Poor → Excellent			Poor → Excellent
17	Internet medical web sites	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
18	Telephone / helpline	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
19	TV / radio	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7

(Please check all that apply and circle the appropriate number)

	Medical Information Sources	***Did*** **you go here for medical information?**		**If "Yes", how good is the quality of information?**	***Will*** **you go here for more medical information?**		**If "Yes", how good do you expect the information to be?**
				Poor → Excellent			**Poor → Excellent**
1	Talking with your physician or physician's assistant	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
2	E-mail from your physician or physician's assistant	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
3	Talking with your physician's nurse / other health professional in their office	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
4	E-mail from physician's nurse / other health professional	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
5	Attending educational program by HMO / hospital	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
6	Talking with a support group	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
7	E-mails from a support group	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
8	Talking with other patients	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
9	E-mails from other patients	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
10	Narratives (written stories by other patients)	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
11	Talking with relatives / friends / acquaintances	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
12	E-mails from relatives / friends / acquaintances	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
13	National / local medical information services (such as the National Institute of Health or the National Cancer Institute)	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
14	Medical leaflets / pamphlets	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
15	Medical journals / Medline / PubMed	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
16	Books	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
17	Internet medical web sites	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
18	Telephone / helpline	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
19	TV / radio	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
20	Newspapers / magazines	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
21	Audio / video tapes	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
22	Films / movies	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7

APPENDIX E: QUESTIONNAIRE VERSION 5

Medical Information Sources Inquiry for Cancer Patients

Instructions

Thanks for taking this two-page survey. The objective of this survey is to investigate the medical information sources you've visited and will visit, and the quality of the medical information you think or you expect from those sources.

Part A asks some background information about you. ***Please answer all the questions in this part by checking the appropriate box.***

Part B investigates the medical information sources you've visited in the past and will visit in the future. There are two sections in this part, Section B1 and B2:

Section B1, which is *on the left*, asks about the medical information sources you've visited in the past. ***Please pick out all the information sources where you FOUND medical information, and evaluate the quality of information that you received from those sources.***

Example: Suppose you ***FOUND*** medical information on Internet medical web sites and Telephone/helpline but not on TV/radio, and you think that the information from Internet medical web sites is of high quality but the information from Telephone/helpline is not very good, your answer should be:

Medical Information Sources		Section B1			Section B2		
		Did you go here for medical information?		If "Yes", how good is the quality of information?	*Will* you go here for more medical information?		If "Yes", how good do you expect the information to be?
				Poor → Excellent			Poor → Excellent
17	Internet medical web sites	☐Yes	☐No	1 2 3 4 5 6 7	☐Yes	☐No	1 2 3 4 5 6 7
18	Telephone / helpline	☐Yes	☐No	1 2 3 4 5 6 7	☐Yes	☐No	1 2 3 4 5 6 7
19	TV / radio	☐Yes	☐No	1 2 3 4 5 6 7	☐Yes	☐No	1 2 3 4 5 6 7

Section B2, which is *on the right*, asks about the medical information you'll visit in the future. ***Please pick out all the information sources that you WILL go to when you are searching for more medical information, and estimate the quality of the information you expect to find.***

Example: In the future, if you ***WILL*** go to Internet medical web sites but not Telephone/helpline or TV/radio when you are searching for ***MORE*** medical information, and you estimate that the quality of the information from Internet medical web sites to be high, your answer should be:

Medical Information Sources		Section B1			Section B2		
		Did you go here for medical information?		If "Yes", how good is the quality of information?	*Will* you go here for more medical information?		If "Yes", how good do you expect the information to be?
				Poor → Excellent			Poor → Excellent
17	Internet medical web sites	☐Yes	☐No	1 2 3 4 5 6 7	☐Yes	☐No	1 2 3 4 5 6 7
18	Telephone / helpline	☐Yes	☐No	1 2 3 4 5 6 7	☐Yes	☐No	1 2 3 4 5 6 7
19	TV / radio	☐Yes	☐No	1 2 3 4 5 6 7	☐Yes	☐No	1 2 3 4 5 6 7

Please answer all the questions in this part by checking the appropriate box.

Part A: Background Information | All information will be kept confidential.

(Please check one box per question)

1	☐ **I am waiting to see the Doctor**	☐ **I have seen the Doctor**
2	☐ **I am currently receiving treatment**	☐ **I am in follow-up**
3	**What type of cancer did or do you have?** ☐ Bladder cancer ☐ Breast cancer ☐ Colon cancer ☐ Endometrial cancer ☐ Head and Neck cancer ☐ Leukemia	☐ Lung cancer ☐ Melanoma ☐ Non-Hodgkin's lymphoma ☐ Ovarian Cancer ☐ Prostate cancer ☐ Rectal cancer ☐ *Other:* _________________
4	**What is your gender?** ☐ Male	☐ Female
5	**What is your age (in years)?** _________	
6	**How would you describe your racial group?** ☐ White (Non Hispanic) ☐ African American ☐ Asian/Pacific Islander	☐ Hispanic or Latin Origin ☐ Bi-racial ☐ *Other:* _________________
7	**What is the highest degree completed by you (the patient)?** ☐ Elementary: 0-8 years ☐ Some High School (no diploma) ☐ High School (With diploma)	☐ Some College ☐ Bachelors degree ☐ Graduate/Professional
8	**What is your working status?** ☐ Working ☐ Full-time sick leave	☐ Retired ☐ Unemployed
9	**Which of the following categories best describes your household income?** ☐ Under $5,000 ☐ $5,000 – $9,999 ☐ $10,000 – $14,999 ☐ $15,000 – $19,999 ☐ $20,000 – $24,999	☐ $25,000 – $34,999 ☐ $35,000 – $49,999 ☐ $50,000 – $74,999 ☐ $75,000 and above
10	**Do you have medical insurance?** ☐ Yes	☐ No
11	**What is your marital status?** ☐ Married/regular partnership	☐ Single/divorced, widowed
12	**Do you have children?** ☐ Yes	☐ No

Part B: Medical Information Sources

All information will be kept confidential.

(Please check all that apply and circle the appropriate number)

	Medical Information Sources	Section B1			Section B2		
		Did you go here for medical information?		If "Yes", how good is the quality of information? Poor → Excellent	***Will*** you go here for more medical information?		If "Yes", how good do you expect the information to be? Poor → Excellent
1	Talking with your physician or physician's assistant	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
2	E-mail from your physician or physician's assistant	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
3	Talking with your physician's nurse / other health professional in their office	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
4	E-mail from physician's nurse / other health professional	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
5	Attending educational program by HMO / hospital	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
6	Talking with a support group	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
7	E-mails from a support group	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
8	Talking with other patients	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
9	E-mails from other patients	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
10	Narratives (written stories by other patients)	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
11	Talking with relatives / friends / acquaintances	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
12	E-mails from relatives / friends / acquaintances	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
13	National / local medical information services *(such as the National Institute of Health or the National Cancer Institute)*	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
14	Medical leaflets / pamphlets	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
15	Medical journals / Medline / PubMed	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
16	Books	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
17	Internet medical web sites	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
18	Telephone / helpline	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
19	TV / radio	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
20	Newspapers / magazines	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
21	Audio / video tapes	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
22	Films / movies	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7

APPENDIX F: QUESTIONNAIRE VERSION 6

Medical Information Sources Inquiry for Cancer Patients

Instructions

Thanks for taking this two-page survey. The objective of this survey is to investigate the medical information sources you've visited and will visit, and the quality of the medical information you think or you expect from those sources.

Part A asks some background information about you. ***Please answer all the questions in this part by checking the appropriate box.***

Part B investigates the medical information sources you've visited in the past and will visit in the future through two sections, Section B1 and B2. **Section B1** asks about the medical information sources you've visited in the past, and **Section B2** asks about the medical information you'll visit in the future. ***Please answer all the questions in this part by checking the appropriate box.***

Part A: Background Information

All information will be kept confidential.

(Please check one box per question)

1	☐ **I am waiting to see the Doctor**	☐ **I have seen the Doctor**
2	☐ **I am currently receiving treatment**	☐ **I am in follow-up**
3	**What type of cancer did or do you have?** ☐ Bladder cancer ☐ Breast cancer ☐ Colon cancer ☐ Endometrial cancer ☐ Head and Neck cancer ☐ Leukemia	☐ Lung cancer ☐ Melanoma ☐ Non-Hodgkin's lymphoma ☐ Ovarian Cancer ☐ Prostate cancer ☐ Rectal cancer ☐ *Other:* __________________
4	**What is your gender?** ☐ Male	☐ Female
5	**What is your age (in years)?** _________	
6	**How would you describe your racial group?** ☐ White (Non Hispanic) ☐ African American ☐ Asian/Pacific Islander	☐ Hispanic or Latin Origin ☐ Bi-racial ☐ *Other:* __________________
7	**What is the highest degree completed by you (the patient)?** ☐ Elementary: 0-8 years ☐ Some High School (no diploma) ☐ High School (With diploma)	☐ Some College ☐ Bachelors degree ☐ Graduate/Professional
8	**What is your working status?** ☐ Working ☐ Full-time sick leave	☐ Retired ☐ Unemployed
9	**Which of the following categories best describes your household income?** ☐ Under $5,000 ☐ $5,000 – $9,999 ☐ $10,000 – $14,999 ☐ $15,000 – $19,999 ☐ $20,000 – $24,999	☐ $25,000 – $34,999 ☐ $35,000 – $49,999 ☐ $50,000 – $74,999 ☐ $75,000 and above
10	**Do you have medical insurance?** ☐ Yes	☐ No
11	**What is your marital status?** ☐ Married/regular partnership	☐ Single/divorced, widowed
12	**Do you have children?** ☐ Yes	☐ No

Part B: Medical Information Sources

All information will be kept confidential.

Example: Suppose 1) you ***FOUND*** medical information both from books and TV/radio, and you think that the information from Books is of high quality but the information from TV/radio is not so good; 2) In the future, you ***WILL*** go to books but not TV/radio when you are searching for ***MORE*** medical information, and you estimate that the quality of the information from books to be high, your answer should be:

	Medical Information Sources	Section B1			Section B2		
		Did you go here for medical information?		If "Yes", how good is the quality of information? **Poor → Excellent**	***Will*** you go here for more medical information?		If "Yes", how good do you expect the information to be? **Poor → Excellent**
16	Books	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
19	TV / radio	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7

(Please check all that apply and circle the appropriate number)

Past **Future**

	Medical Information Sources	Section B1			Section B2		
		Did you go here for medical information?		If "Yes", how good is the quality of information? **Poor → Excellent**	***Will*** you go here for more medical information?		If "Yes", how good do you expect the information to be? **Poor → Excellent**
1	Talking with your physician or physician's assistant	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
2	E-mail from your physician or physician's assistant	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
3	Talking with your physician's nurse / other health professional in their office	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
4	E-mail from physician's nurse / other health professional	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
5	Attending educational program by HMO / hospital	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7

Past **Future**

	Medical Information Sources (Continue)	Section B1			Section B2		
		Did you go here for medical information?		If "Yes", how good is the quality of information?	*Will* you go here for more medical information?		If "Yes", how good do you expect the information to be?
				Poor → Excellent			**Poor → Excellent**
6	Talking with a support group	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
7	E-mails from a support group	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
8	Talking with other patients	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
9	E-mails from other patients	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
10	Narratives (written stories by other patients)	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
11	Talking with relatives / friends / acquaintances	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
12	E-mails from relatives / friends / acquaintances	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
13	National / local medical information services *(such as the National Institute of Health or the National Cancer Institute)*	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
14	Medical leaflets / pamphlets	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
15	Medical journals / Medline / PubMed	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
16	Books	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
17	Internet medical web sites	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
18	Telephone / helpline	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
19	TV / radio	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
20	Newspapers / magazines	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
21	Audio / video tapes	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7
22	Films / movies	☐ Yes	☐No	1 2 3 4 5 6 7	☐ Yes	☐No	1 2 3 4 5 6 7

APPENDIX G: QUESTIONNAIRE VERSION 7

Chen Wang, Graduate Student
Management of Technology Program
Vanderbilt University
Tel: 615-322-7769

David Dilts, PhD, MBA
Professor & Director, Graduate Studies
Management of Technology Program
Vanderbilt University
Tel: 615-322-3479
Fax: 615-322-7996

Dear Participant,

I am a graduate student in the Management of Technology program at Vanderbilt University, working with Dr. David Dilts. The objective of my research is to investigate where cancer patients find information and what they feel about the quality of such information. We also wish to investigate where you may go in the future for more information and what you believe the quality of that information may be.

Your responses to the survey will only be used for purpose of this study and not for any diagnostic or medical purposes. All individual responses are completely confidential. Completing the survey is entirely voluntary, and by doing so you consent to having the survey information used in the study.

The survey takes about **10-15 minutes**. There are three parts to the survey. The first part asks general background questions. The second part asks about sources of medical information. The third part presents you with four scenarios and asks your opinion of how likely you are to do something.

You may refuse to answer any question at any time and, again, all individual responses will be entirely confidential and anonymous.

This survey has been supported by the Vanderbilt Ingram Cancer Center and has been reviewed and received approval from the Institutional Review Board at Vanderbilt University. For questions concerning this study or survey, please contact Chen Wang at 615-322-7769, or Dr. David Dilts at 615-322-3479, or the Institutional Review Board at 615-322-2918 and 866-224-8273 (toll free).

Thank you very much for your time. Your input will help us to evaluate better ways to deliver health care information to patients.

Chen Wang
Management of Technology Program
Vanderbilt University

Medical Information Sources For Cancer Patients

Instructions

Thanks for taking this survey. The objective of this survey is to investigate the medical information sources you have visited in the past and may visit in the future.

Part A

In this part, we will ask background information. All individual responses will be kept completely confidential.
Please answer the questions in this part by checking the appropriate box.

Part B

This part is divided into two sections.

Section B1 asks about the medical information sources you've visited in the past; **Section B2** asks about the medical information you'll visit in the future.

Please answer the questions in this part by checking the appropriate box.

Version 7

Part A: Background Information

All information will be kept confidential.

(Please check one box or circle one answer per question.)

I'm filling in this questionnaire ☐ **as a patient** ☐ **for a patient I'm accompanying**

1	**What is your gender?** ☐ Male	☐ Female
2	**What is your age (in years)?** _________	
3	**How would you describe your racial group?** ☐ White (Non Hispanic) ☐ African American ☐ Asian/Pacific Islander	☐ Hispanic or Latin Origin ☐ Bi-racial: ________________ ☐ *Other:* _________________
4	**What is the highest degree completed by you?** ☐ Elementary: 0-8 years ☐ Some high school (no diploma) ☐ High school (with diploma)	☐ Some college ☐ Bachelor's degree ☐ Graduate/professional
5	**What is your working status?** ☐ Working ☐ Full-time sick leave	☐ Retired ☐ Unemployed
6	**Which of the following categories best describes your household income?** ☐ Under $5,000 ☐ $ 5,000 – $ 9,999 ☐ $10,000 – $14,999 ☐ $15,000 – $19,999 ☐ $20,000 – $24,999	☐ $25,000 – $34,999 ☐ $35,000 – $49,999 ☐ $50,000 – $74,999 ☐ $75,000 and above
7	**Do you have medical insurance?** ☐ Yes	☐ No
8	**What is your marital status?** ☐ Married/regular partnership	☐ Single/divorced, widowed
9	**Do you have children?** ☐ Yes	☐ No
10	**What type of cancer did or do you have?** ☐ Bladder cancer ☐ Breast cancer ☐ Colon cancer ☐ Endometrial cancer ☐ Head and neck cancer ☐ Leukemia	☐ Lung cancer ☐ Melanoma ☐ Non-Hodgkin's lymphoma ☐ Ovarian cancer ☐ Prostate cancer ☐ Rectal cancer ☐ *Other:* _________________
11	☐ **I am currently receiving treatment**	☐ **I am in follow-up**

Part B: Medical Information Sources

All information will be kept confidential.

There are a number of sources of medical information. For example, you could have heard something on TV or you could have searched the Internet. We are interested in your opinion of each source, so each has a separate question.

There are four elements to each question in this section:

1. First, **have** you used the specific source for medical information in the **past**?
2. Second, what is your opinion of the quality of the information found from this source in the **past**?
3. Third, **will** you use this medical source for information in the **future**?
4. What is your opinion of the expected quality of the information you will gather from this source in the **future?**

EXAMPLE Suppose you have **FOUND** medical information from *Books* in the past and you believe that the quality of information from *Books* was excellent. You should check "Yes" in Section B1, and circle "7" the quality of information. Suppose you **WILL** continue to use *Books* as a source of information in the future and you expect that the quality of information will continue to be excellent. You should check "Yes" in Section B2 and circle "7" for quality of information.

Suppose you **FOUND** medical information *TV/radio* and believe that the quality of information from *TV/radio* was poor, then in B1 you would check "Yes" and circle "1". Suppose you **WILL** not search for more medical information from *TV/radio*, then you should check "no" and leave the quality of information scale blank.

Medical information sources in the ***PAST***

Quality Scale

1 = Very Poor
2 = Poor
3 = Below Average
4 = Average
5 = Good
6 = Very Good
7 = Excellent

Medical information sources in the ***FUTURE***

Medical Information Sources		**Section B1 - PAST**		**Section B2 - FUTURE**	
		Did **you get Medical information from this source?**	**If "Yes", how good was the information quality?** **Very Poor → Excellent**	***Will*** **you get Medical information from this source in the future?**	**If "Yes", how good do you expect the information to be?** **Very Poor → Excellent**
16	Books	☒ Yes ☐ No	1…2…3…4…5…6…[✓ 7]	☒ Yes ☐ No	1…2…3…4…5…6…[✓ 7]
19	TV/radio	☒ Yes ☐ No	[✓ 1]…2…3…4…5…6…7	☐ Yes ☒ No	1…2…3…4…5…6…7

Please check all that apply and circle the appropriate number.

Medical information sources in the PAST

Quality Scale

1 = Very Poor
2 = Poor
3 = Below Average
4 = Average
5 = Good
6 = Very Good
7 = Excellent

Medical information sources in the FUTURE

	Medical Information Sources	**Section B1 - PAST**		**Section B2 - FUTURE**	
		Did **you get Medical information from this source?**	**If "Yes", how good was the information quality? Very Poor → Excellent**	***Will*** **you get Medical information from this source?**	**If "Yes", how good do you expect the information quality? Very Poor → Excellent**
1	Talking with physician or physician's assistant	☐ Yes ☐ No	1…2…3…4…5…6…7	☐ Yes ☐ No	1…2…3…4…5…6…7
2	E-mail from physician or physician's assistant	☐ Yes ☐ No	1…2…3…4…5…6…7	☐ Yes ☐ No	1…2…3…4…5…6…7
3	Talking with nurse/other health professionals	☐ Yes ☐ No	1…2…3…4…5…6…7	☐ Yes ☐ No	1…2…3…4…5…6…7
4	E-mail from nurse/other health professionals	☐ Yes ☐ No	1…2…3…4…5…6…7	☐ Yes ☐ No	1…2…3…4…5…6…7
5	Attending educational program by HMO/hospital	☐ Yes ☐ No	1…2…3…4…5…6…7	☐ Yes ☐ No	1…2…3…4…5…6…7
6	Talking with a support group	☐ Yes ☐ No	1…2…3…4…5…6…7	☐ Yes ☐ No	1…2…3…4…5…6…7
7	E-mail/Chat-room with a support group	☐ Yes ☐ No	1…2…3…4…5…6…7	☐ Yes ☐ No	1…2…3…4…5…6…7
8	Talking with other patients	☐ Yes ☐ No	1…2…3…4…5…6…7	☐ Yes ☐ No	1…2…3…4…5…6…7
9	E-mail/Chat-room with other patients	☐ Yes ☐ No	1…2…3…4…5…6…7	☐ Yes ☐ No	1…2…3…4…5…6…7
10	Narratives (written stories by other patients)	☐ Yes ☐ No	1…2…3…4…5…6…7	☐ Yes ☐ No	1…2…3…4…5…6…7
11	Talking with relatives/friends/acquaintances	☐ Yes ☐ No	1…2…3…4…5…6…7	☐ Yes ☐ No	1…2…3…4…5…6…7
12	E-mails from relatives/friends/acquaintances	☐ Yes ☐ No	1…2…3…4…5…6…7	☐ Yes ☐ No	1…2…3…4…5…6…7
13	Message Board	☐ Yes ☐ No	1…2…3…4…5…6…7	☐ Yes ☐ No	1…2…3…4…5…6…7
14	National/local medical information services *(e.g. National Institute of Health/National Cancer Institute)*	☐ Yes ☐ No	1…2…3…4…5…6…7	☐ Yes ☐ No	1…2…3…4…5…6…7
15	Medical leaflets/pamphlets	☐ Yes ☐ No	1…2…3…4…5…6…7	☐ Yes ☐ No	1…2…3…4…5…6…7
16	Medical journals/Medline/Pub Med	☐ Yes ☐ No	1…2…3…4…5…6…7	☐ Yes ☐ No	1…2…3…4…5…6…7
17	Books	☐ Yes ☐ No	1…2…3…4…5…6…7	☐ Yes ☐ No	1…2…3…4…5…6…7
18	Internet medical web sites	☐ Yes ☐ No	1…2…3…4…5…6…7	☐ Yes ☐ No	1…2…3…4…5…6…7
19	Telephone/helpline	☐ Yes ☐ No	1…2…3…4…5…6…7	☐ Yes ☐ No	1…2…3…4…5…6…7
20	TV/radio	☐ Yes ☐ No	1…2…3…4…5…6…7	☐ Yes ☐ No	1…2…3…4…5…6…7
21	Newspapers/magazines	☐ Yes ☐ No	1…2…3…4…5…6…7	☐ Yes ☐ No	1…2…3…4…5…6…7
22	Audio/video tapes	☐ Yes ☐ No	1…2…3…4…5…6…7	☐ Yes ☐ No	1…2…3…4…5…6…7
23	Films/movies	☐ Yes ☐ No	1…2…3…4…5…6…7	☐ Yes ☐ No	1…2…3…4…5…6…7

APPENDIX H: QUESTIONNAIRE VERSION 8

Chen Wang, Graduate Student
Management of Technology Program
Vanderbilt University
Tel: 615-322-7769

David Dilts, PhD, MBA
Professor & Director, Graduate Studies
Management of Technology Program
Vanderbilt University
Tel: 615-322-3479
Fax: 615-322-7996

Dear Participant,

I am a graduate student in the Management of Technology program at Vanderbilt University, working with Dr. David Dilts. The objective of my research is to investigate where cancer patients and their companions find information and what they feel about the quality of such information. We also wish to investigate where they may go in the future for more information and what they believe the quality of that information may be.

Your responses to the survey will only be used for purpose of this study and not for any diagnostic or medical purposes. All individual responses are completely confidential. Completing the survey is entirely voluntary, and by doing so you consent to having the survey information used in the study.

The survey takes about **10-15 minutes**. There are three parts to the survey. The first part asks general background questions. The second part asks about sources of medical information. The third part presents you with four scenarios and asks your opinion of how likely you are to do something.

You may refuse to answer any question at any time and, again, all individual responses will be entirely confidential and anonymous.

This survey has been supported by the Vanderbilt Ingram Cancer Center and has been reviewed and received approval from the Institutional Review Board at Vanderbilt University. For questions concerning this study or survey, please contact Chen Wang at 615-322-7769, or Dr. David Dilts at 615-322-3479, or the Institutional Review Board at 615-322-2918 and 866-224-8273 (toll free).

Thank you very much for your time. Your input will help us to evaluate better ways to deliver health care information to patients.

Chen Wang
Management of Technology Program
Vanderbilt University

Version 8

Medical Information Sources For Cancer Patients

Instructions

Thanks for taking this survey. The objective of this survey is to investigate the medical information sources you have visited in the past and may visit in the future, including your estimation of the quality of such medical information. Additional interest is your opinions about some related medical situations.

Part A In this part, we ask background information.
All individual responses will be kept completely confidential.

Please answer the questions in this part by checking the appropriate box.

Part B This part is divided into three sections.

Section B1 asks about the medical information sources, including those you have visited in the past and you'll visit in the future.
Section B2 asks about the specific medical topics, including those you have searched in the past and that you may search in the future.
Section B3 asks about specific websites, including those you have visited in the past and you'll visit in the future.

Please answer the questions in this part by checking the appropriate box.

Version 8

Part A: Background Information

All information will be kept confidential.

(Please check one box or circle one answer per question.)

1 **I'm** ☐ **patient**

☐ **companion** *If "companion", please answer:*

What's your relationship to the patient? ___________________________

Do you live in the same household? ☐ Yes ☐ No

2 **What is your gender?** ☐ Male ☐ Female

3 **What is your age (in years)?** _________

4 **How would you describe your racial group?**

☐ White (Non Hispanic)
☐ African American
☐ Asian/Pacific Islander
☐ Hispanic or Latin Origin
☐ Bi-racial: _______________________
☐ *Other:* _________________________

5 **What is the highest degree completed by you?**

☐ Elementary: 0-8 years
☐ Some high school (no diploma)
☐ High school (with diploma)
☐ Some college
☐ Bachelor's degree
☐ Graduate/professional

6 **What is your working status?** ☐ Working ☐ Retired ☐ Full-time sick leave ☐ Unemployed

7 **Which of the following categories best describes your household income?**

☐ Under $5,000
☐ $ 5,000 – $ 9,999
☐ $10,000 – $14,999
☐ $15,000 – $19,999
☐ $20,000 – $24,999
☐ $25,000 – $34,999
☐ $35,000 – $49,999
☐ $50,000 – $74,999
☐ $75,000 and above

8 **Do you have medical insurance?** ☐ Yes ☐ No

9 **What is your marital status?** ☐ Married/regular partnership ☐ Single/divorced, widowed

10 **Do you have children?** ☐ Yes ☐ No

11 **Do you own a computer?** ☐ Yes ☐ No

12 **Do you have Internet access?** ☐ Yes ☐ No

13 **What type of cancer did or do you have?**

☐ Bladder cancer
☐ Breast cancer
☐ Colon cancer
☐ Endometrial cancer
☐ Head/Neck cancer
☐ Leukemia
☐ Lung cancer
☐ Melanoma
☐ Non-Hodgkin's lymphoma
☐ Ovarian cancer
☐ Prostate cancer
☐ Rectal cancer
☐ *Other:* _______________________

14 **What was the date of your diagnosis?** (mm/dd/yy) _______________________

15 ☐ **I am currently receiving treatment** ☐ **I am in follow-up**

Part B: Medical Information Sources

All information will be kept confidential.

Section B1 There are a number of sources of medical information. For example, you could have heard something on TV or you could have searched the Internet. We are interested in your opinion of each source, so each has a separate question.

There are four elements to each question in this section:

1. **Have** you used the specific source for medical information in the **past**?
2. What is your opinion of the quality of the information found from this source in the **past**?
3. **Will** you use this medical source for information in the **future**?
4. What is your opinion of the expected quality of the information you will gather from this source in the **future?**

EXAMPLE

1. Suppose you have **FOUND** medical information from *Books* in the past and you believe that the quality of information from *Books* was excellent. You should check "Yes" in ***"PAST"*** column, and circle "7" the quality of information. Suppose you **WILL** continue to use *Books* as a source of information in the future and you expect that the quality of information will continue to be excellent. You should check "Yes" in ***"FUTURE"*** column and circle "7" for quality of information.

2. Suppose you **FOUND** medical information *TV/radio* and believe that the quality of information from *TV/radio* was poor, then in ***"PAST"*** column you would check "Yes" and circle "1". Suppose you **WILL not** search for more medical information from *TV/radio*, then you should leave "***FUTURE***" column (both the check box and the quality of information scale) blank.

Medical information sources in the ***PAST***

Quality Scale
1 = Very Poor
2 = Poor
3 = Below Average
4 = Average
5 = Good
6 = Very Good
7 = Excellent

Medical information sources in the ***FUTURE***

Medical Information Sources		**PAST**		**FUTURE**	
		Did **you get Medical information from this source?**	**If "Yes", how good was the information quality?** **Very Poor → Excellent**	***Will*** **you get medical information from this source?**	**If "Yes", how good do you expect the information to be?** **Very Poor → Excellent**
1	Books	☒ Yes	1…2…3…4…5…6…[✓ 7]	☒ Yes	1…2…3…4…5…6…[✓ 7]
2	TV/radio	☒ Yes	[✓ 1]…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7

Medical information sources in the ***PAST***

Quality Scale

1 = Very Poor
2 = Poor
3 = Below Average
4 = Average
5 = Good
6 = Very Good
7 = Excellent

Medical information sources in the ***FUTURE***

Section B1: **Please check all that apply and circle the appropriate number.**

Medical Information Sources		**PAST**		**FUTURE**	
		Did **you get Medical information from this source?**	**If "Yes", how good was the information quality?** **Very Poor → Excellent**	***Will*** **you get Medical information from this source?**	**If "Yes", how good do you expect the information quality?** **Very Poor → Excellent**
1	Talking with physician or physician's assistant	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
2	Talking with nurse/other health professionals	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
3	Talking with a support group	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
4	Talking with other patients	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
5	Talking with relatives/friends/acquaintances	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
6	E-mail from physician or physician's assistant	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
7	E-mail from nurse/other health professionals	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
8	E-mail/Chat-room with a support group	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
9	E-mail/Chat-room with other patients	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
10	E-mails from relatives/friends/acquaintances	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
11	Educational programs by HMO/hospital	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
12	National/local medical information services (NIH/NCI)	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
13	Medical leaflets/pamphlets	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
14	Narratives (written stories by other patients)	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
15	Message Board	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
16	Books	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
17	Medical journals	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
18	Internet/medical websites	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
19	Telephone/helpline	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
20	TV/radio	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
21	Newspapers/magazines	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
22	Audio/video tapes	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
23	Films/movies	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7

Section B2 There are a number of medical topics that may be of interest. For example, you could have searched information for pain management. We are interested in your experience of each topic, so each has a separate question.

There are two elements to each question in this section:

1. What **were** the specific medical topics you've searched in the **past**?
2. What **will be** the specific medical topics you will search in the **future**?

XAMPLE

1. Suppose you **DID** search information about Diagnosis and Treatment in the past, you should check "Yes" in ***"PAST"*** column. Suppose you **WILL** continue to search information about Diagnosis and Treatment in the future, you should check "Yes" in ***"FUTURE"*** column.
2. Suppose you **DID not** search information about Complementary and Alternative Medicine in the past, you should leave the check box blank in ***"PAST"*** column. Suppose you **WILL** start to search information about Complementary and Alternative Medicine in the future, you should check "Yes" in ***"FUTURE"*** column.

Specific Medical Topics		PAST Check ☒ if you *searched* this topic	FUTURE Check ☒ if you *will* search this topic
1	Diagnosis and Treatment	☒ Yes	☒ Yes
2	Complementary and Alternative Medicine	☐ Yes	☒ Yes

Others (please list):

Cancer Terminology Resource

Section B2: Please check all that apply and list topics not included

Specific Medical Topics		PAST Check ☒ if you *searched* this topic	FUTURE Check ☒ if you *will* search this topic
1	Diagnosis and Treatment	☐ Yes	☐ Yes
2	Complementary and Alternative Medicine	☐ Yes	☐ Yes
3	Clinical Trials and Genetics Services	☐ Yes	☐ Yes
4	Coping with Cancer (side effects and complications)	☐ Yes	☐ Yes
5	Pain Management	☐ Yes	☐ Yes
6	Cancer Biology	☐ Yes	☐ Yes
7	Drugs and side effects	☐ Yes	☐ Yes
8	Nutrition	☐ Yes	☐ Yes
9	Patient Experiences	☐ Yes	☐ Yes
10	Cancer Prevention/Genetics/Causes	☐ Yes	☐ Yes
11	Cancer Physicians	☐ Yes	☐ Yes
12	Cancer Hospitals	☐ Yes	☐ Yes
13	Support and Resources	☐ Yes	☐ Yes
14	Insurance/Financial Assistance	☐ Yes	☐ Yes
15	Cancer Literature	☐ Yes	☐ Yes

Others (please list):

____

____

____

____

____

____

____

____

____

Section B3 There are a number of Internet websites. For example, you could have visited National Cancer Institute for medical information. We are interested in your experience of each website, so each has a separate question.

There are two elements to each question in this section:

1. If you've used Internet for medical information in the **past**, which were the specific websites?
2. If you will **begin** or **continue** to use Internet for medical information in the **future**, which websites will you visit?

EXAMPLE

1. Suppose you **DID** visit MSKCC for medical information in the past, you should check "Yes" in ***"PAST"*** column. Suppose you **WILL** continue to visit MSKCC for medical information in the future, you should check "Yes" in ***"FUTURE"*** column.
2. Suppose you **DID** visit NCI for medical information in the past, you should check box "Yes" in ***"PAST"*** column. Suppose you **WILL not** visit NCI for medical information in the future, you should leave the check box blank in ***"FUTURE"*** column.

	Specific Internet Websites	PAST Check ☒ if you *searched* this topic	FUTURE Check ☒ if you *will* search this topic
1	MSKCC (www.mskcc.org)	☒ Yes	☒ Yes
2	NCI (www.cancer.gov)	☒ Yes	☐ Yes

Others (please list):

www.cancerlinksusa.com

Section B3: Please check all that apply and list websites not included

	Specific Internet Websites	PAST Check ☒ if you *visited* this website	FUTURE Check ☒ if you *will* visit this website
1	National Cancer Institute (www.cancer.gov)	☐ Yes	☐ Yes
2	National Institute of Health (www.nih.gov)	☐ Yes	☐ Yes
3	American Cancer Society (www.cancer.org)	☐ Yes	☐ Yes
4	PDQ Database	☐ Yes	☐ Yes
5	CancerTrials (www.cancertrials.com)	☐ Yes	☐ Yes
6	Amer. Society of Clinical Oncologist (www.asco.org)	☐ Yes	☐ Yes
7	CancerHelp (www.cancerhelp.com)	☐ Yes	☐ Yes
8	Mayo Clinic (www.mayoclinic.org)	☐ Yes	☐ Yes
9	Oncolink (www.oncolink.com)	☐ Yes	☐ Yes
10	Memorial Sloan-Kettering Cancer C. (www.mskcc.org)	☐ Yes	☐ Yes
11	Medicine Online (www.medicineonline.com)	☐ Yes	☐ Yes
12	M.D. Anderson Cancer Center (www.mdanderson.org)	☐ Yes	☐ Yes
13	Caner Support Network (www.serve.com/csni)	☐ Yes	☐ Yes
14	Oncology Online (www.asco.org)	☐ Yes	☐ Yes
15	WebDoctor (ww.webdoctor.com)	☐ Yes	☐ Yes

	Specific Internet Websites	PAST Check ☒ if you *visited* this website	FUTURE Check ☒ if you *will* visit this website
16	CenterWatch (www.centerwatch.com)	☐ Yes	☐ Yes
17	WebMD (www.webmd.com)	☐ Yes	☐ Yes
18	PubMed (www.pubmed.com)	☐ Yes	☐ Yes
19	Onhealth (www.onhealth.com)	☐ Yes	☐ Yes
20	PharmWeb (www.pharmweb.net)	☐ Yes	☐ Yes
21	Search Engines (Google/Yahoo)	☐ Yes	☐ Yes

Others (please list):

____

____

____

APPENDIX I: QUESTIONNAIRE VERSION 9

Chen Wang, Graduate Student
Management of Technology Program
Vanderbilt University
Tel: 615-322-7769

David Dilts, PhD, MBA
Professor & Director, Graduate Studies
Management of Technology Program
Vanderbilt University
Tel: 615-322-3479
Fax: 615-322-7996

Dear Participant,

I am a graduate student in the Management of Technology program at Vanderbilt University, working with Dr. David Dilts. The objective of my research is to investigate where cancer patients and their companions find information and what they feel about the quality of such information. We also wish to investigate where they may go in the future for more information and what they believe the quality of that information may be.

Your responses to the survey will only be used for purpose of this study and not for any diagnostic or medical purposes. All individual responses are completely confidential. Completing the survey is entirely voluntary, and by doing so you consent to having the survey information used in the study.

The survey takes about **10-15 minutes**. There are three parts to the survey. The first part asks general background questions. The second part asks about sources of medical information. The third part presents you with four scenarios and asks your opinion of how likely you are to do something.

You may refuse to answer any question at any time and, again, all individual responses will be entirely confidential and anonymous.

This survey has been supported by the Vanderbilt Ingram Cancer Center and has been reviewed and received approval from the Institutional Review Board at Vanderbilt University. For questions concerning this study or survey, please contact Chen Wang at 615-322-7769, or Dr. David Dilts at 615-322-3479, or the Institutional Review Board at 615-322-2918 and 866-224-8273 (toll free).

Thank you very much for your time. Your input will help us to evaluate better ways to deliver health care information to patients.

Chen Wang
Management of Technology Program
Vanderbilt University

Medical Information Sources For Cancer Patients

Instructions

Thanks for taking this survey. The objective of this survey is to investigate the medical information sources you have visited in the past and may visit in the future, including your estimation of the quality of such medical information. Additional interest is your opinions about some related medical situations.

Part A

In this part, we ask background information.
All individual responses will be kept completely confidential.

Please answer the questions in this part by checking the appropriate box.

Part B

This part is divided into three sections.

Section B1 asks about the medical information sources, including those you have visited in the past and you'll visit in the future.
Section B2 asks about the specific medical topics, including those you have searched in the past and that you may search in the future.
Section B3 asks about specific websites, including those you have visited in the past and you'll visit in the future.

Please answer the questions in this part by checking the appropriate box.

Part A: Background Information

All information will be kept confidential.

(Please check one box or circle one answer per question.)

1 **I'm ☐ patient**

☐ companion *If "companion", please answer:*

What's your relationship to the patient? ___________________________

Do you live in the same household? ☐ Yes ☐ No

2 **What is your gender?** ☐ Male ☐ Female

3 **What is your age (in years)?** _________

4 **How would you describe your racial group?**

☐ White (Non Hispanic) ☐ Hispanic or Latin Origin

☐ African American ☐ Bi-racial: _______________________

☐ Asian/Pacific Islander ☐ *Other:* _________________________

5 **What is the highest degree completed by you?**

☐ Elementary: 0-8 years ☐ Some college

☐ Some high school (no diploma) ☐ Bachelor's degree

☐ High school (with diploma) ☐ Graduate/professional

6 **What is your working status?** ☐ Working ☐ Retired

☐ Full-time sick leave ☐ Unemployed

7 **Which of the following categories best describes your household income?**

☐ Under $5,000 ☐ $15,000 – $19,999 ☐ $35,000 – $49,999

☐ $ 5,000 – $ 9,999 ☐ $20,000 – $24,999 ☐ $50,000 – $74,999

☐ $10,000 – $14,999 ☐ $25,000 – $34,999 ☐ $75,000 and above

8 **Do you have medical insurance?** ☐ Yes ☐ No

9 **What is your marital status?** ☐ Married/regular partnership ☐ Single/divorced, widowed

10 **Do you have children?** ☐ Yes ☐ No

11 **Do you own a computer?** ☐ Yes ☐ No

12 **Do you have Internet access?** ☐ Yes ☐ No

13 **What type of cancer did or do you have?** ☐ Non-Hodgkin's lymphoma

☐ Bladder cancer ☐ Head/Neck cancer ☐ Ovarian cancer

☐ Breast cancer ☐ Leukemia ☐ Prostate cancer

☐ Colon cancer ☐ Lung cancer ☐ Rectal cancer

☐ Endometrial cancer ☐ Melanoma ☐ *Other:* ________________________

14 **What was the date of your diagnosis?** (mm/dd/yy) _______________________

15 **☐ I am currently receiving treatment** **☐ I am in follow-up**

16 (***Opinion question)*** From a range of not at all important *[1]* to critically important *[7]*, Do you believe the years of experience of a physician should influence a patient's choice of taking a recommended treatment? ***(Please circle one)***

not at all important [1…2…3…4…5…6…7]critical to the choice

17 (***Opinion question)*** From a range of not at all important *[1]* to critically important *[7]*, Do you believe the years a pharmaceutical firm has manufactured a drug should influence a patient's choice of a drug? ***(Please circle one)***

Part B: Medical Information Sources

All information will be kept confidential.

Section B1

There are a number of sources of medical information. For example, you could have heard something on TV or you could have searched the Internet. We are interested in your opinion of each source, so each has a separate question.

There are four elements to each question in this section:

1. **Have** you used the specific source for medical information in the **past**?
2. What is your opinion of the quality of the information found from this source in the **past**?
3. **Will** you use this medical source for information in the **future**?
4. What is your opinion of the expected quality of the information you will gather from this source in the **future?**

EXAMPLE

1. Suppose you have **FOUND** medical information from *Books* in the past and you believe that the quality of information from *Books* was excellent. You should check "Yes" in ***"PAST"*** column, and circle "7" the quality of information. Suppose you **WILL** continue to use *Books* as a source of information in the future and you expect that the quality of information will continue to be excellent. You should check "Yes" in ***"FUTURE"*** column and circle "7" for quality of information.

2. Suppose you **FOUND** medical information *TV/radio* and believe that the quality of information from *TV/radio* was poor, then in ***"PAST"*** column you would check "Yes" and circle "1". Suppose you **WILL not** search for more medical information from *TV/radio*, then you should leave "***FUTURE***" column (both the check box and the quality of information scale) blank.

Medical information sources in the ***PAST***

Quality Scale

1 = Very Poor
2 = Poor
3 = Below Average
4 = Average
5 = Good
6 = Very Good
7 = Excellent

Medical information sources in the ***FUTURE***

Medical Information Sources		**PAST**		**FUTURE**	
		Did **you get Medical information from this source?**	**If "Yes", how good was the information quality?** **Very Poor → Excellent**	***Will*** **you get medical information from this source?**	**If "Yes", how good do you expect the information to be?** **Very Poor → Excellent**
1	Books	☒ Yes	1…2…3…4…5…6…[✓ 7]	☒ Yes	1…2…3…4…5…6…[✓ 7]
2	TV/radio	☒ Yes	[✓ 1]…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7

Quality Scale

1 = Very Poor
2 = Poor
3 = Below Average
4 = Average
5 = Good
6 = Very Good
7 = Excellent

Medical information sources in the ***PAST***

Medical information sources in the ***FUTURE***

Section B1: **Please check all that apply and circle the appropriate number.**

		PAST		FUTURE	
	Medical Information Sources	***Did*** **you get Medical information from this source?**	**If "Yes", how good was the information quality?** **Very Poor → Excellent**	***Will*** **you get Medical information from this source?**	**If "Yes", how good do you expect the information quality?** **Very Poor → Excellent**
1	Talking with physician or physician's assistant	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
2	Talking with nurse/other health professionals	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
3	Talking with a support group	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
4	Talking with other patients	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
5	Talking with relatives/friends/acquaintances	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
6	E-mail from physician or physician's assistant	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
7	E-mail from nurse/other health professionals	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
8	E-mail/Chat-room with a support group	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
9	E-mail/Chat-room with other patients	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
10	E-mails from relatives/friends/acquaintances	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
11	Educational programs by HMO/hospital	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
12	National/local medical information services (NIH/NCI)	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
13	Medical leaflets/pamphlets	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
14	Narratives (written stories by other patients)	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
15	Message Board	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
16	Books	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
17	Medical journals	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
18	Internet/medical websites	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
19	Telephone/helpline	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
20	TV/radio	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
21	Newspapers/magazines	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
22	Audio/video tapes	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
23	Films/movies	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7

Section B2

There are a number of medical topics that may be of interest. For example, you could have searched information for pain management. We are interested in your experience of each topic, so each has a separate question.

There are two elements to each question in this section:

1. What **were** the specific medical topics you've searched in the **past**?
2. What **will be** the specific medical topics you will search in the **future**?

EXAMPLE

1. Suppose you **DID** search information about Diagnosis and Treatment in the past, you should check "Yes" in ***"PAST"*** column. Suppose you **WILL** continue to search information about Diagnosis and Treatment in the future, you should check "Yes" in ***"FUTURE"*** column.

2. Suppose you **DID not** search information about Complementary and Alternative Medicine in the past, you should leave the check box blank in ***"PAST"*** column. Suppose you **WILL** start to search information about Complementary and Alternative Medicine in the future, you should check "Yes" in ***"FUTURE"*** column.

	Specific Medical Topics	PAST Check ☒ if you *searched* this topic	FUTURE Check ☒ if you *will* search this topic
1	Diagnosis and Treatment	☒ Yes	☒ Yes
2	Complementary and Alternative Medicine	☐ Yes	☒ Yes

Others (please list):

Cancer Terminology Resource

Section B2: Please check all that apply and list topics not included

	Specific Medical Topics	PAST Check ☒ if you *searched* this topic	FUTURE Check ☒ if you *will* search this topic
1	Diagnosis and Treatment	☐ Yes	☐ Yes
2	Complementary and Alternative Medicine	☐ Yes	☐ Yes
3	Clinical Trials and Genetics Services	☐ Yes	☐ Yes
4	Coping with Cancer (side effects and complications)	☐ Yes	☐ Yes
5	Pain Management	☐ Yes	☐ Yes
6	Cancer Biology	☐ Yes	☐ Yes
7	Drugs and side effects	☐ Yes	☐ Yes
8	Nutrition	☐ Yes	☐ Yes
9	Patient Experiences	☐ Yes	☐ Yes
10	Cancer Prevention/Genetics/Causes	☐ Yes	☐ Yes
11	Cancer Physicians	☐ Yes	☐ Yes
12	Cancer Hospitals	☐ Yes	☐ Yes
13	Support and Resources	☐ Yes	☐ Yes
14	Insurance/Financial Assistance	☐ Yes	☐ Yes
15	Cancer Literature	☐ Yes	☐ Yes

Others (please list):

____

____

____

____

____

____

____

____

____

Section B3

There are a number of Internet websites. For example, you could have visited National Cancer Institute for medical information. We are interested in your experience of each website, so each has a separate question.

There are two elements to each question in this section:

1. If you've used Internet for medical information in the **past**, which were the specific websites?
2. If you will **begin** or **continue** to use Internet for medical information in the **future**, which websites will you visit?

EXAMPLE

1. Suppose you **DID** visit MSKCC for medical information in the past, you should check "Yes" in ***"PAST"*** column. Suppose you **WILL** continue to visit MSKCC for medical information in the future, you should check "Yes" in ***"FUTURE"*** column.
2. Suppose you **DID** visit NCI for medical information in the past, you should check box "Yes" in ***"PAST"*** column. Suppose you **WILL not** visit NCI for medical information in the future, you should leave the check box blank in ***"FUTURE"*** column.

Specific Internet Websites		PAST Check ☒ if you *searched* this topic	FUTURE Check ☒ if you *will* search this topic
1	MSKCC (www.mskcc.org)	☒ Yes	☒ Yes
2	NCI (www.cancer.gov)	☒ Yes	☐ Yes

Others (please list):

__*www.cancerlinksusa.com*__

Section B3: Please check all that apply and list websites not included

Specific Internet Websites		PAST Check ☒ if you *visited* this website	FUTURE Check ☒ if you *will* visit this website
1	National Cancer Institute (www.cancer.gov)	☐ Yes	☐ Yes
2	National Institute of Health (www.nih.gov)	☐ Yes	☐ Yes
3	American Cancer Society (www.cancer.org)	☐ Yes	☐ Yes
4	PDQ Database	☐ Yes	☐ Yes
5	CancerTrials (www.cancertrials.com)	☐ Yes	☐ Yes
6	Amer. Society of Clinical Oncologist (www.asco.org)	☐ Yes	☐ Yes
7	CancerHelp (www.cancerhelp.com)	☐ Yes	☐ Yes
8	Mayo Clinic (www.mayoclinic.org)	☐ Yes	☐ Yes
9	Oncolink (www.oncolink.com)	☐ Yes	☐ Yes
10	Memorial Sloan-Kettering Cancer C. (www.mskcc.org)	☐ Yes	☐ Yes
11	Medicine Online (www.medicineonline.com)	☐ Yes	☐ Yes
12	M.D. Anderson Cancer Center (www.mdanderson.org)	☐ Yes	☐ Yes
13	Caner Support Network (www.serve.com/csni)	☐ Yes	☐ Yes
14	Oncology Online (www.asco.org)	☐ Yes	☐ Yes
15	WebDoctor (ww.webdoctor.com)	☐ Yes	☐ Yes

Specific Internet Websites		PAST Check ☒ if you *visited* this website	FUTURE Check ☒ if you *will* visit this website
16	CenterWatch (www.centerwatch.com)	☐ Yes	☐ Yes
17	WebMD (www.webmd.com)	☐ Yes	☐ Yes
18	PubMed (www.pubmed.com)	☐ Yes	☐ Yes
19	Onhealth (www.onhealth.com)	☐ Yes	☐ Yes
20	PharmWeb (www.pharmweb.net)	☐ Yes	☐ Yes
21	Search Engines (Google/Yahoo)	☐ Yes	☐ Yes

Others (please list):

____

____

____

APPENDIX J: FINAL QUESTIONNAIRE

Chen Wang, Graduate Student
Management of Technology Program
Vanderbilt University
Tel: 615-322-7769

David Dilts, PhD, MBA
Professor & Director, Graduate Studies
Management of Technology Program
Vanderbilt University
Tel: 615-322-3479
Fax: 615-322-7996

Dear Participant,

I am a graduate student in the Management of Technology program at Vanderbilt University, working with Dr. David Dilts. The objective of my research is to investigate where cancer patients and their companions find information about cancer and what they feel about the quality of such information. We also wish to investigate where they may go in the future for more information and what they believe the quality of that information may be.

Your responses to the survey will only be used for purpose of this study and not for any diagnostic or medical purposes. All individual responses are completely confidential. Completing the survey is entirely voluntary, and by doing so you consent to having the survey information used in the study.

The survey takes about **10-15 minutes**. There are three parts to the survey. The first part asks general background questions. The second part asks about sources of medical information. The third part presents you with four scenarios and asks your opinion of how likely you are to do something.

You may refuse to answer any question at any time and, again, all individual responses will be entirely confidential and anonymous.

This survey has been supported by the Vanderbilt Ingram Cancer Center and has been reviewed and received approval from the Institutional Review Board at Vanderbilt University. For questions concerning this study or survey, please contact Chen Wang at 615-322-7769, or Dr. David Dilts at 615-322-3479, or the Institutional Review Board at 615-322-2918 and 866-224-8273 (toll free).

Thank you very much for your time. Your input will help us to evaluate better ways to deliver health care information to patients.

Final Version

Medical Information Sources For Cancer Patients

Instructions

Thanks for taking this survey. The objective of this survey is to investigate the medical information sources you have visited in the past and may visit in the future, including your estimation of the quality of such medical information. Additional interest is your opinions about some related medical situations.

Part A In this part, we ask background information.
All individual responses will be kept completely confidential.

Part B This part is divided into three sections.

Section B1 asks about the medical information sources, including those you have visited in the past and you'll visit in the future.
Section B2 asks about the specific medical topics, including those you have searched in the past and that you may search in the future.
Section B3 asks about specific websites, including those you have visited in the past and you'll visit in the future.

Part C In this part, we ask some "yes or no" questions about information benefits and how you view each.

Part A: Background Information All information will be kept confidential.

Please check one box or circle one answer per question.

1 **Are you a patient or the companion?**

☐ **patient** *If "patient", please answer:*

a. What type of cancer did or do you have?

☐ Bladder cancer
☐ Brain cancer
☐ Breast cancer
☐ Colon cancer
☐ Endometrial cancer
☐ Head/Neck cancer
☐ Leukemia
☐ Lung cancer
☐ Melanoma
☐ Non-Hodgkin's lymphoma
☐ Ovarian cancer
☐ Prostate cancer
☐ Rectal cancer
☐ *Other:* _______________

b. What was the date of your diagnosis? (mm/dd/yy) _______________________

c. You're currently ☐ **receiving treatment** ☐ **in follow-up**

☐ **companion** *If "companion", please answer:*

a. What's your relationship to the patient? ________________________________

b. Do you live in the same household? ☐ Yes ☐ No

2 **What is your gender?** ☐ Male ☐ Female

3 **What is your age (in years)?** _________

4 **How would you describe your racial group?**

☐ White (Non Hispanic)
☐ African American
☐ Asian/Pacific Islander
☐ Hispanic or Latin Origin
☐ Bi-racial: _______________________
☐ *Other:* _________________________

5 **What is the highest degree completed by you?**

☐ Elementary: 0-8 years
☐ Some high school (no diploma)
☐ High school (with diploma)
☐ Some college
☐ Bachelor's degree
☐ Graduate/professional

6 **What is your working status?**

☐ Working ☐ Full-time sick leave ☐ Retired ☐ Unemployed

7 **Which of the following categories best describes your household income?**

☐ Under $5,000
☐ $ 5,000 – $ 9,999
☐ $10,000 – $14,999
☐ $15,000 – $19,999
☐ $20,000 – $24,999
☐ $25,000 – $34,999
☐ $35,000 – $49,999
☐ $50,000 – $74,999
☐ $75,000 and above

8 **Do you have medical insurance?** ☐ Yes ☐ No

9 **What is your marital status?** ☐ Married/regular partnership ☐ Single/divorced, widowed

10 **Do you have children?** ☐ Yes ☐ No

11 **Do you own a computer?** ☐ Yes ☐ No

12 **Do you have Internet access?** ☐ Yes ☐ No

13 (***Opinion question)*** From a range of not at all important *[1]* to critically important *[7]*, Do you believe the years of experience of a physician should influence a patient's choice of taking a recommended treatment? ***(Please circle one)***

not at all important [1…2…3…4…5…6…7]critical to the choice

Part B: Medical Information Sources

All information will be kept confidential.

Instructions of Section B1: Sources

Guidelines There are a number of sources of medical information. For example, you could have heard something on TV or have searched the Internet. We are interested in your opinion of each source, so each has a separate question.

There are four elements to each question in this section:

1. **Have** you used the specific source for medical information in the **past**?
2. What is your opinion of the quality of the information found from this source in the **past**?
3. **Will** you use this medical source for information in the **future**?
4. What is your opinion of the expected quality of the information you will gather from this source in the **future?**

Examples **1.**Suppose you have **FOUND** medical information from *Books* in the past and you believe that the quality of information from *Books* was excellent. You should check "Yes" in ***"PAST"*** column, and circle "7" the quality of information. Suppose you **WILL** continue to use *Books* as a source of information in the future and you expect that the quality of information will continue to be excellent. You should check "Yes" in ***"FUTURE"*** column and circle "7" for quality of information.

2.Suppose you **FOUND** medical information *TV/radio* and believe that the quality of information from *TV/radio* was poor, then in ***"PAST"*** column you would check "Yes" and circle "1". Suppose you **WILL not** search for more medical information from *TV/radio*, then you should leave "***FUTURE***" column (both the check box and the quality of information scale) blank.

Quality Scale
1 = Very Poor
2 = Poor
3 = Below Average
4 = Average
5 = Good
6 = Very Good
7 = Excellent

		PAST (sources you've used)		**FUTURE** (sources you feel you may use)	
Medical Information Sources		***Did*** **you get Medical information from this source?**	**If "Yes", how good was the information quality?** **Very Poor → Excellent**	***Will*** **you get medical information from this source?**	**If "Yes", how good do you expect the information to be?** **Very Poor → Excellent**
1	Books	☒ Yes	1…2…3…4…5…6…[✓ 7]	☒ Yes	1…2…3…4…5…6…[✓ 7]
2	TV/radio	☒ Yes	[✓ 1]…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7

EXAMPLE PAGE

Section B1: Sources

Please check all that apply and circle the appropriate number.

	Medical Information Sources	**PAST** (sources you've used)		**FUTURE** (sources you feel you may use)	
		Did you get Medical information from this source?	If "Yes", how good was the information quality? Very Poor → Excellent	***Will*** you get Medical information from this source?	If "Yes", how good do you expect the information quality? Very Poor → Excellent
1	Talking with physician or physician's assistant	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
2	Talking with nurse/other health professionals	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
3	Talking with a support group	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
4	Talking with other patients	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
5	Talking with relatives/friends/acquaintances	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
6	E-mail from physician or physician's assistant	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
7	E-mail from nurse/other health professionals	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
8	E-mail/Chat-room with a support group	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
9	E-mail/Chat-room with other patients	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
10	E-mails from relatives/friends/acquaintances	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
11	Educational programs by HMO/hospital	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
12	National/local medical information services (NIH/NCI)	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
13	Medical leaflets/pamphlets	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
14	Narratives (written stories by other patients)	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
15	Message Board	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
16	Books	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
17	Medical journals	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
18	Internet/medical websites	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
19	Telephone/helpline	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
20	TV/radio	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
21	Newspapers/magazines	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
22	Audio/video tapes	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7
23	Films/movies	☐ Yes	1…2…3…4…5…6…7	☐ Yes	1…2…3…4…5…6…7

Section B2: Topics

Please check the topic which you searched or will search, and list topics not included.

	Specific Medical Topics	**PAST** (topics you've searched)	**FUTURE** (topics you feel you may search)
1	Diagnosis and Treatment	☐ Yes	☐ Yes
2	Complementary and Alternative Medicine	☐ Yes	☐ Yes
3	Clinical Trials and Genetics Services	☐ Yes	☐ Yes
4	Coping with Cancer (side effects and complications)	☐ Yes	☐ Yes
5	Pain Management	☐ Yes	☐ Yes
6	Cancer Biology	☐ Yes	☐ Yes
7	Drugs and side effects	☐ Yes	☐ Yes
8	Nutrition	☐ Yes	☐ Yes
9	Patient Experiences	☐ Yes	☐ Yes
10	Cancer Prevention/Genetics/Causes	☐ Yes	☐ Yes
11	Oncologists	☐ Yes	☐ Yes
12	Cancer Hospitals	☐ Yes	☐ Yes
13	Support and Resources	☐ Yes	☐ Yes
14	Insurance/Financial Assistance	☐ Yes	☐ Yes
15	Cancer Literature	☐ Yes	☐ Yes

Others (please list):

____
____
____
____
____
____
____
____
____

Section B3: Websites – *SKIP if you've never used any Internet Website*

Please check all that apply and list websites that are not included.

	Specific Internet Websites	**PAST** (websites you've visited)	**FUTURE** (websites you may visit)
1	National Cancer Institute (www.cancer.gov)	☐ Yes	☐ Yes
2	National Institute of Health (www.nih.gov)	☐ Yes	☐ Yes
3	American Cancer Society (www.cancer.org)	☐ Yes	☐ Yes
4	PDQ Database	☐ Yes	☐ Yes
5	CancerTrials (www.cancertrials.com)	☐ Yes	☐ Yes
6	Amer. Society of Clinical Oncologist (www.asco.org)	☐ Yes	☐ Yes
7	CancerHelp (www.cancerhelp.com)	☐ Yes	☐ Yes
8	Mayo Clinic (www.mayoclinic.org)	☐ Yes	☐ Yes
9	Oncolink (www.oncolink.com)	☐ Yes	☐ Yes
10	Memorial Sloan-Kettering Cancer C. (www.mskcc.org)	☐ Yes	☐ Yes
11	Medicine Online (www.medicineonline.com)	☐ Yes	☐ Yes
12	M.D. Anderson Cancer Center (www.mdanderson.org)	☐ Yes	☐ Yes
13	Caner Support Network (www.serve.com/csni)	☐ Yes	☐ Yes
14	Oncology Online (www.asco.org)	☐ Yes	☐ Yes
15	WebDoctor (www.webdoctor.com)	☐ Yes	☐ Yes

	Specific Internet Websites	**PAST** (websites you've visited)	**FUTURE** (websites you may visit)
16	CenterWatch (www.centerwatch.com)	☐ Yes	☐ Yes
17	WebMD (www.webmd.com)	☐ Yes	☐ Yes
18	PubMed (www.pubmed.com)	☐ Yes	☐ Yes
19	Onhealth (www.onhealth.com)	☐ Yes	☐ Yes
20	PharmWeb (www.pharmweb.net)	☐ Yes	☐ Yes
21	Search Engines (Google/Yahoo)	☐ Yes	☐ Yes

Others (please list):

____
____
____

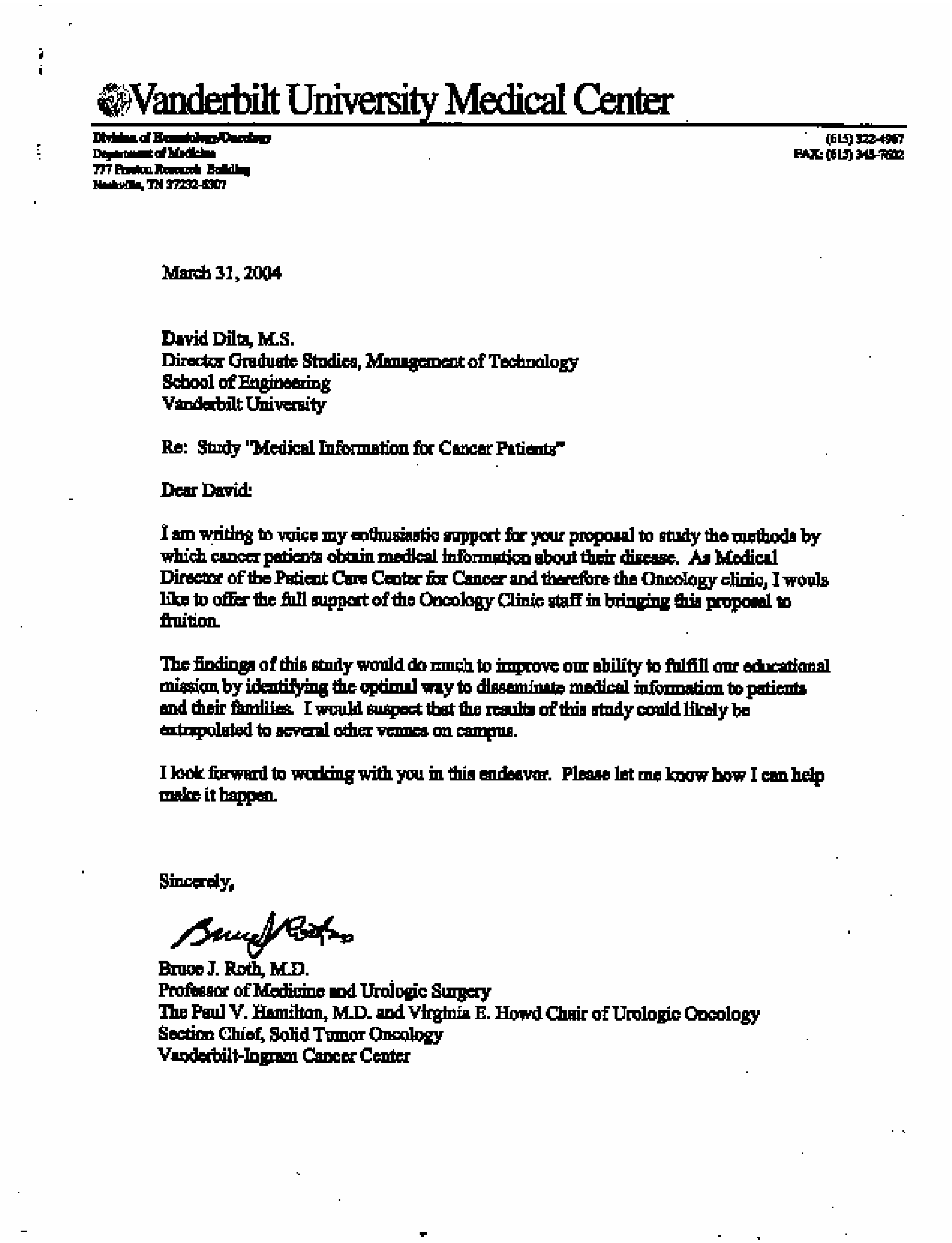
Part C: Information Benefits

There are several benefits patients can get from information. We'd like to know your opinions about that.
Please check *"Yes"* or *"No"* for the following questions about information benefits:

1. ☐ Yes ☐ No Information increases your involvement in decision making.
2. ☐ Yes ☐ No Information increases your satisfaction with treatment choices.
3. ☐ Yes ☐ No Information improves your ability to cope during the diagnosis, treatment and post-treatment phases.
4. ☐ Yes ☐ No Information reduces your anxiety and mood disturbances.
5. ☐ Yes ☐ No Information improves communication between you and your family members.

Thank you!

APPENDIX K: SUPPORT LETTER FROM VICC



Vanderbilt University Medical Center

Division of Hematology/Oncology
Department of Medicine
777 Preston Research Building
Nashville, TN 37232-6307

(615) 322-4967
FAX: (615) 343-7602

March 31, 2004

David Dilts, M.S.
Director Graduate Studies, Management of Technology
School of Engineering
Vanderbilt University

Re: Study "Medical Information for Cancer Patients"

Dear David:

I am writing to voice my enthusiastic support for your proposal to study the methods by which cancer patients obtain medical information about their disease. As Medical Director of the Patient Care Center for Cancer and therefore the Oncology clinic, I would like to offer the full support of the Oncology Clinic staff in bringing this proposal to fruition.

The findings of this study would do much to improve our ability to fulfill our educational mission by identifying the optimal way to disseminate medical information to patients and their families. I would suspect that the results of this study could likely be extrapolated to several other venues on campus.

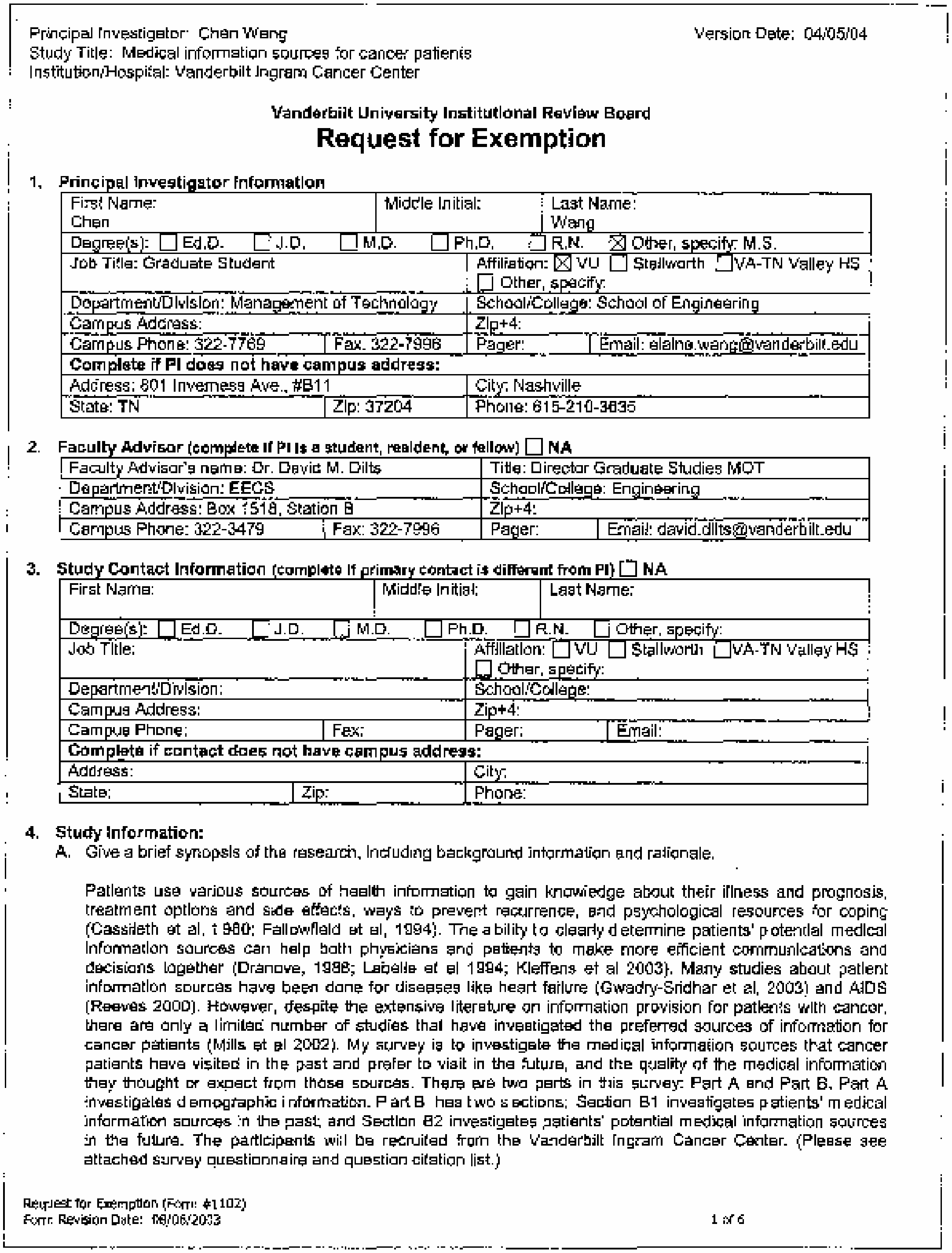
I look forward to working with you in this endeavor. Please let me know how I can help make it happen.

Sincerely,

Bruce J. Roth, M.D.
Professor of Medicine and Urologic Surgery
The Paul V. Hamilton, M.D. and Virginia E. Howd Chair of Urologic Oncology
Section Chief, Solid Tumor Oncology
Vanderbilt-Ingram Cancer Center

APPENDIX L: PROPOSAL SUMMITTED TO IRB

April 05, 2004



Principal Investigator: Chen Wang
Study Title: Medical information sources for cancer patients
Institution/Hospital: Vanderbilt Ingram Cancer Center

Version Date: 04/05/04

Vanderbilt University Institutional Review Board

Request for Exemption

1. **Principal Investigator Information**

First Name: Chen	Middle Initial:	Last Name: Wang
Degree(s): ☐ Ed.D. ☐ J.D. ☐ M.D. ☐ Ph.D. ☐ R.N. ☒ Other, specify: M.S.		
Job Title: Graduate Student	Affiliation: ☒ VU ☐ Stallworth ☐ VA-TN Valley HS ☐ Other, specify:	
Department/Division: Management of Technology	School/College: School of Engineering	
Campus Address:	Zip+4:	
Campus Phone: 322-7769	Fax: 322-7996	Pager:	Email: elaine.wang@vanderbilt.edu
Complete if PI does not have campus address:		
Address: 801 Inverness Ave., #B11	City: Nashville	
State: TN	Zip: 37204	Phone: 615-210-3635

2. **Faculty Advisor (complete if PI is a student, resident, or fellow)** ☐ **NA**

Faculty Advisor's name: Dr. David M. Dilts		Title: Director Graduate Studies MOT	
Department/Division: EECS		School/College: Engineering	
Campus Address: Box 1518, Station B		Zip+4:	
Campus Phone: 322-3479	Fax: 322-7996	Pager:	Email: david.dilts@vanderbilt.edu

3. **Study Contact Information (complete if primary contact is different from PI)** ☐ **NA**

First Name:	Middle Initial:	Last Name:	
Degree(s): ☐ Ed.D. ☐ J.D. ☐ M.D. ☐ Ph.D. ☐ R.N. ☐ Other, specify:			
Job Title:		Affiliation: ☐ VU ☐ Stallworth ☐ VA-TN Valley HS ☐ Other, specify:	
Department/Division:		School/College:	
Campus Address:		Zip+4:	
Campus Phone:	Fax:	Pager:	Email:
Complete if contact does not have campus address:			
Address:		City:	
State:	Zip:	Phone:	

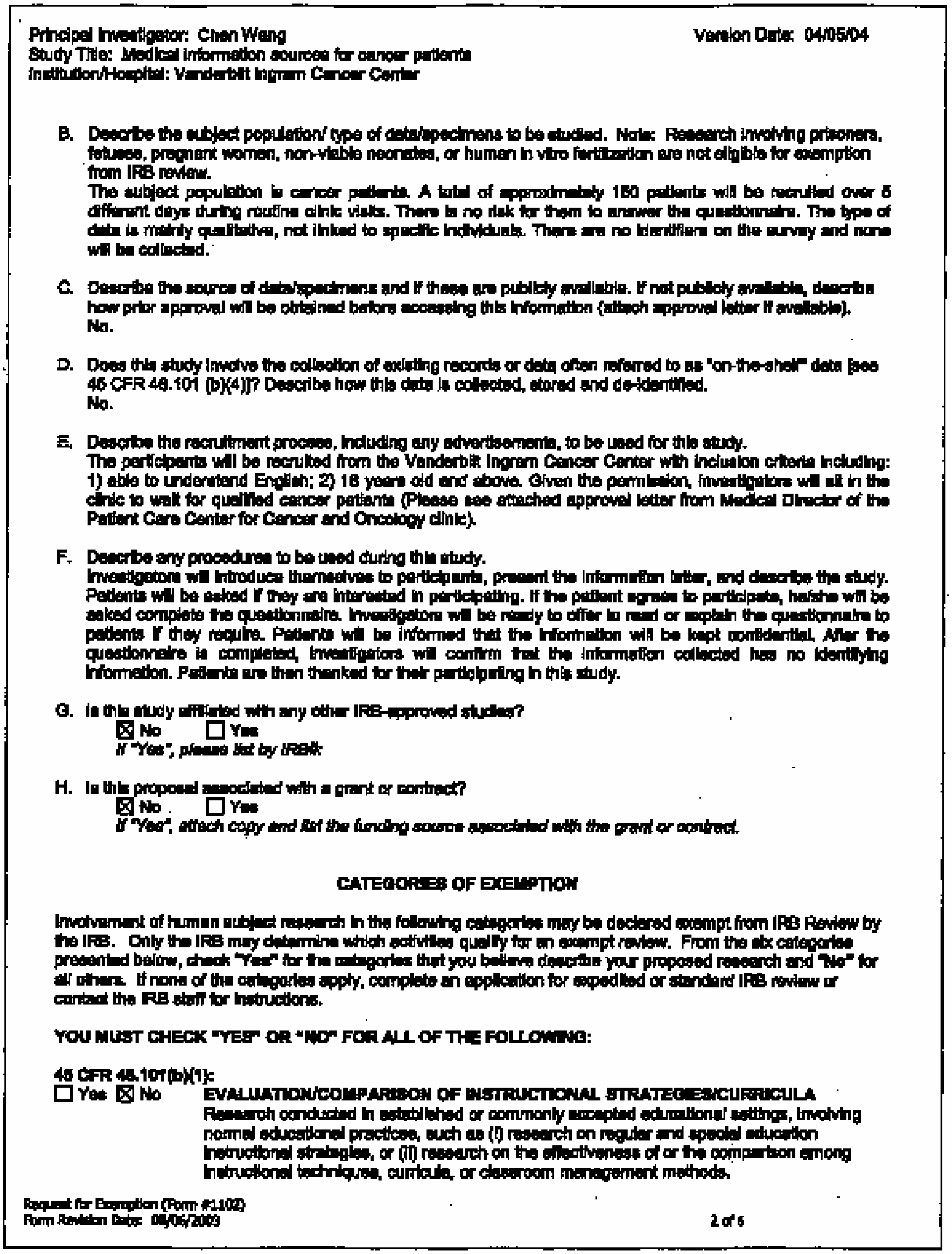
4. **Study Information:**

   A. Give a brief synopsis of the research, including background information and rationale.

   Patients use various sources of health information to gain knowledge about their illness and prognosis, treatment options and side effects, ways to prevent recurrence, and psychological resources for coping (Cassileth et al, 1980; Fallowfield et al, 1994). The ability to clearly determine patients' potential medical information sources can help both physicians and patients to make more efficient communications and decisions together (Dranove, 1998; Labelle et al 1994; Kleffens et al 2003). Many studies about patient information sources have been done for diseases like heart failure (Gwadry-Sridhar et al, 2003) and AIDS (Reeves 2000). However, despite the extensive literature on information provision for patients with cancer, there are only a limited number of studies that have investigated the preferred sources of information for cancer patients (Mills et al 2002). My survey is to investigate the medical information sources that cancer patients have visited in the past and prefer to visit in the future, and the quality of the medical information they thought or expect from those sources. There are two parts in this survey: Part A and Part B. Part A investigates demographic information. Part B has two sections; Section B1 investigates patients' medical information sources in the past; and Section B2 investigates patients' potential medical information sources in the future. The participants will be recruited from the Vanderbilt Ingram Cancer Center. (Please see attached survey questionnaire and question citation list.)

Request for Exemption (Form #1102)
Form Revision Date: 08/06/2003

1 of 6



Principal Investigator: Chen Wang **Version Date: 04/05/04**
Study Title: Medical information sources for cancer patients
Institution/Hospital: Vanderbilt Ingram Cancer Center

B. Describe the subject population/ type of data/specimens to be studied. Note: Research involving prisoners, fetuses, pregnant women, non-viable neonates, or human in vitro fertilization are not eligible for exemption from IRB review.
The subject population is cancer patients. A total of approximately 150 patients will be recruited over 5 different days during routine clinic visits. There is no risk for them to answer the questionnaire. The type of data is mainly qualitative, not linked to specific individuals. There are no identifiers on the survey and none will be collected.

C. Describe the source of data/specimens and if these are publicly available. If not publicly available, describe how prior approval will be obtained before accessing this information (attach approval letter if available).
No.

D. Does this study involve the collection of existing records or data often referred to as "on-the-shelf" data [see 45 CFR 46.101 (b)(4)]? Describe how this data is collected, stored and de-identified.
No.

E. Describe the recruitment process, including any advertisements, to be used for this study.
The participants will be recruited from the Vanderbilt Ingram Cancer Center with inclusion criteria including: 1) able to understand English; 2) 18 years old and above. Given the permission, investigators will sit in the clinic to wait for qualified cancer patients (Please see attached approval letter from Medical Director of the Patient Care Center for Cancer and Oncology clinic).

F. Describe any procedures to be used during this study.
Investigators will introduce themselves to participants, present the information letter, and describe the study. Patients will be asked if they are interested in participating. If the patient agrees to participate, he/she will be asked complete the questionnaire. Investigators will be ready to offer to read or explain the questionnaire to patients if they require. Patients will be informed that the information will be kept confidential. After the questionnaire is completed, investigators will confirm that the information collected has no identifying information. Patients are then thanked for their participating in this study.

G. Is this study affiliated with any other IRB-approved studies?
☒ No ☐ Yes
If "Yes", please list by IRB#:

H. Is this proposal associated with a grant or contract?
☒ No ☐ Yes
If "Yes", attach copy and list the funding source associated with the grant or contract.

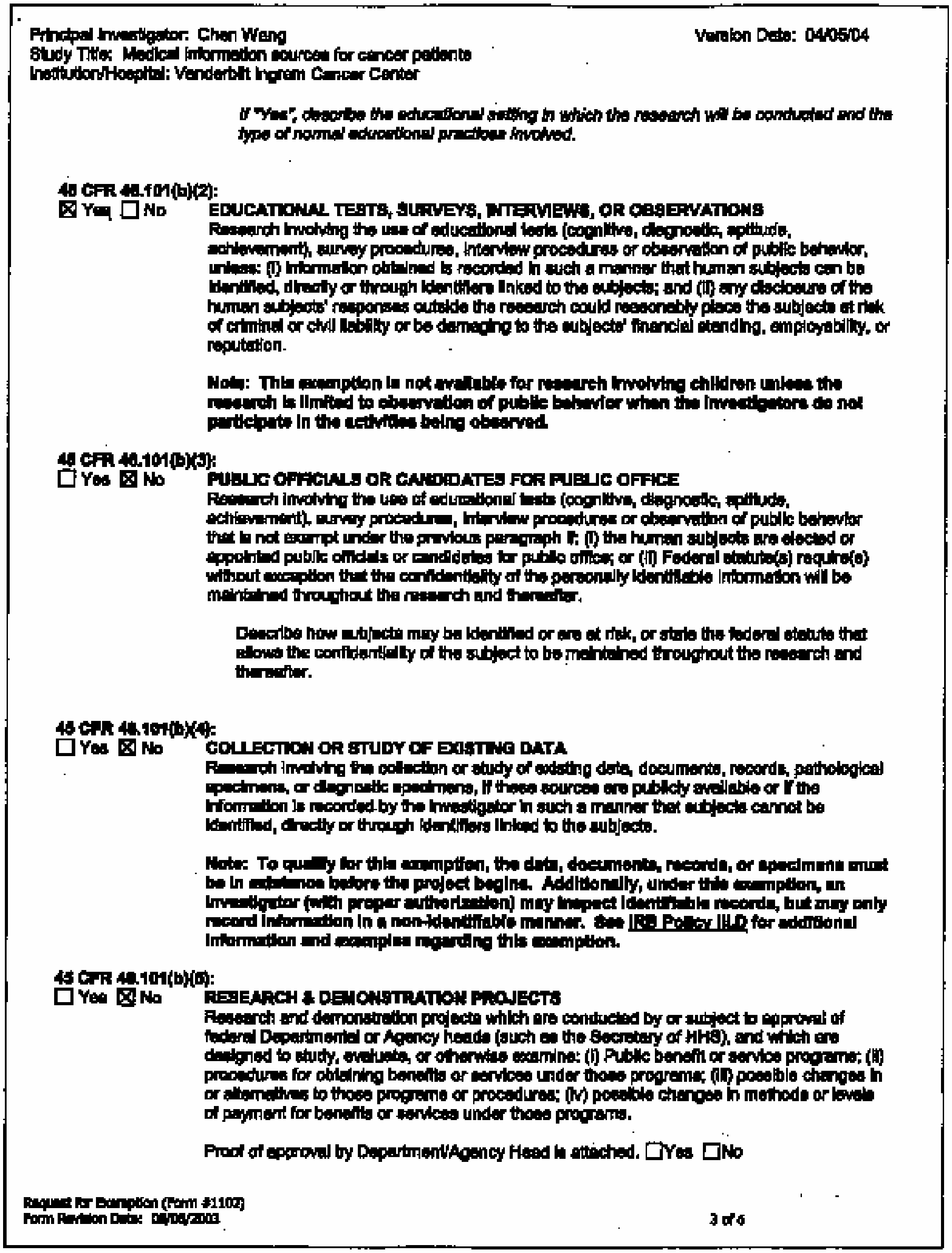
CATEGORIES OF EXEMPTION

Involvement of human subject research in the following categories may be declared exempt from IRB Review by the IRB. Only the IRB may determine which activities qualify for an exempt review. From the six categories presented below, check "Yes" for the categories that you believe describe your proposed research and "No" for all others. If none of the categories apply, complete an application for expedited or standard IRB review or contact the IRB staff for instructions.

YOU MUST CHECK "YES" OR "NO" FOR ALL OF THE FOLLOWING:

45 CFR 46.101(b)(1):
☐ Yes ☒ No **EVALUATION/COMPARISON OF INSTRUCTIONAL STRATEGIES/CURRICULA**
Research conducted in established or commonly accepted educational settings, involving normal educational practices, such as (i) research on regular and special education instructional strategies, or (ii) research on the effectiveness of or the comparison among instructional techniques, curricula, or classroom management methods.

Request for Exemption (Form #1102)
Form Revision Date: 08/06/2003 2 of 6



If "Yes", describe the educational setting in which the research will be conducted and the type of normal educational practices involved.

45 CFR 46.101(b)(2):
☒ Yes ☐ No **EDUCATIONAL TESTS, SURVEYS, INTERVIEWS, OR OBSERVATIONS**

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.

Note: This exemption is not available for research involving children unless the research is limited to observation of public behavior when the investigators do not participate in the activities being observed.

45 CFR 46.101(b)(3):
☐ Yes ☒ No **PUBLIC OFFICIALS OR CANDIDATES FOR PUBLIC OFFICE**

Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior that is not exempt under the previous paragraph if: (i) the human subjects are elected or appointed public officials or candidates for public office; or (ii) Federal statute(s) require(s) without exception that the confidentiality of the personally identifiable information will be maintained throughout the research and thereafter.

Describe how subjects may be identified or are at risk, or state the federal statute that allows the confidentiality of the subject to be maintained throughout the research and thereafter.

45 CFR 46.101(b)(4):
☐ Yes ☒ No **COLLECTION OR STUDY OF EXISTING DATA**

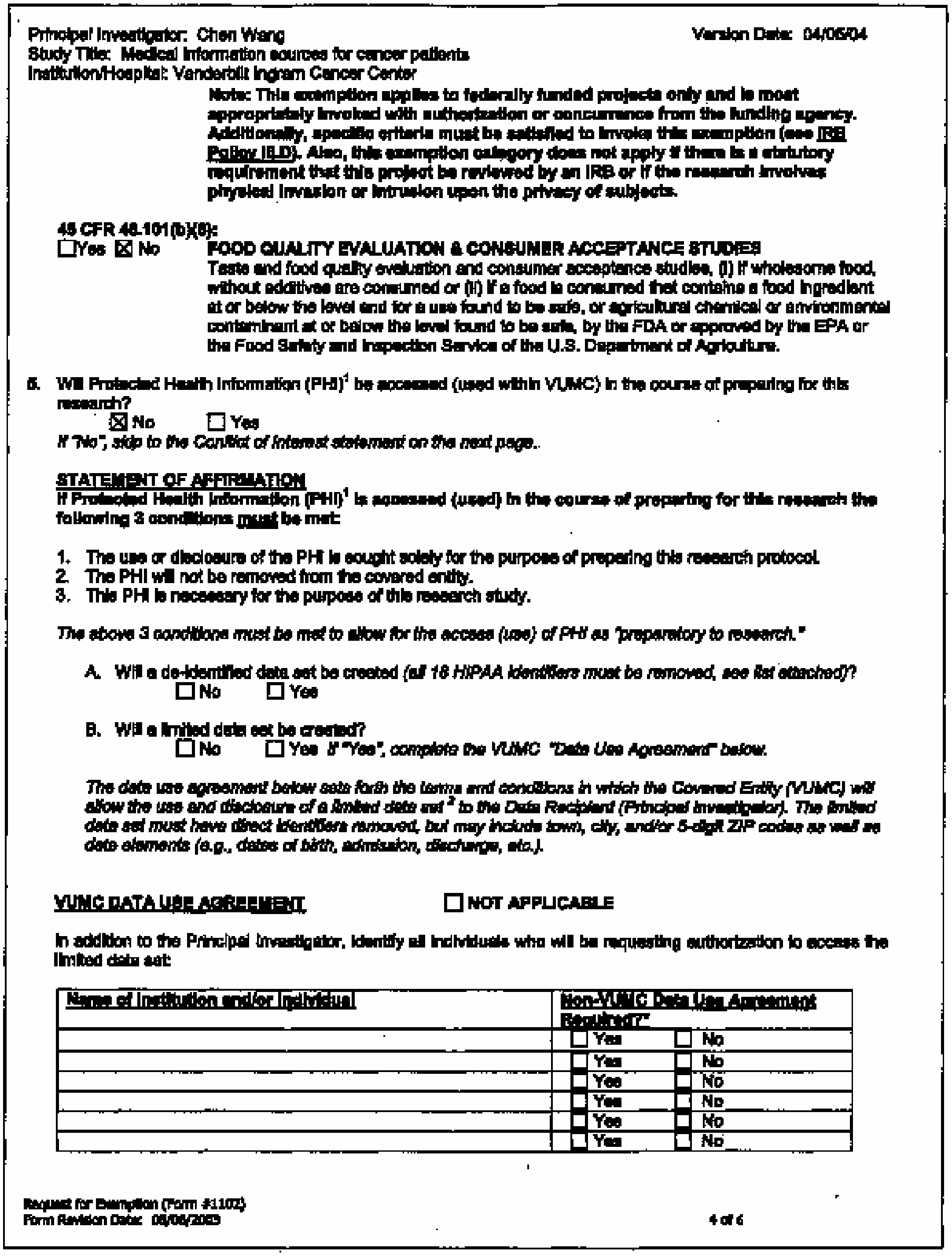
Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these sources are publicly available or if the information is recorded by the investigator in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects.

Note: To qualify for this exemption, the data, documents, records, or specimens must be in existence before the project begins. Additionally, under this exemption, an investigator (with proper authorization) may inspect identifiable records, but may only record information in a non-identifiable manner. See IRB Policy III.D for additional information and examples regarding this exemption.

45 CFR 46.101(b)(5):
☐ Yes ☒ No **RESEARCH & DEMONSTRATION PROJECTS**

Research and demonstration projects which are conducted by or subject to approval of federal Departmental or Agency heads (such as the Secretary of HHS), and which are designed to study, evaluate, or otherwise examine: (i) Public benefit or service programs; (ii) procedures for obtaining benefits or services under those programs; (iii) possible changes in or alternatives to those programs or procedures; (iv) possible changes in methods or levels of payment for benefits or services under those programs.

Proof of approval by Department/Agency Head is attached. ☐Yes ☐No



Principal Investigator: Chen Wang **Version Date:** 04/06/04
Study Title: Medical information sources for cancer patients
Institution/Hospital: Vanderbilt Ingram Cancer Center

Note: This exemption applies to federally funded projects only and is most appropriately invoked with authorization or concurrence from the funding agency. Additionally, specific criteria must be satisfied to invoke this exemption (see IRB Policy III.D). Also, this exemption category does not apply if there is a statutory requirement that this project be reviewed by an IRB or if the research involves physical invasion or intrusion upon the privacy of subjects.

45 CFR 46.101(b)(6):
☐Yes ☒ No **FOOD QUALITY EVALUATION & CONSUMER ACCEPTANCE STUDIES**
Taste and food quality evaluation and consumer acceptance studies, (i) if wholesome food, without additives are consumed or (ii) if a food is consumed that contains a food ingredient at or below the level and for a use found to be safe, or agricultural chemical or environmental contaminant at or below the level found to be safe, by the FDA or approved by the EPA or the Food Safety and Inspection Service of the U.S. Department of Agriculture.

6. Will Protected Health Information (PHI)[1] be accessed (used within VUMC) in the course of preparing for this research?
☒ No ☐ Yes
If "No", skip to the Conflict of Interest statement on the next page..

STATEMENT OF AFFIRMATION
If Protected Health Information (PHI)[1] is accessed (used) in the course of preparing for this research the following 3 conditions must be met:

1. The use or disclosure of the PHI is sought solely for the purpose of preparing this research protocol.
2. The PHI will not be removed from the covered entity.
3. This PHI is necessary for the purpose of this research study.

The above 3 conditions must be met to allow for the access (use) of PHI as "preparatory to research."

A. Will a de-identified data set be created *(all 18 HIPAA identifiers must be removed, see list attached)*?
☐ No ☐ Yes

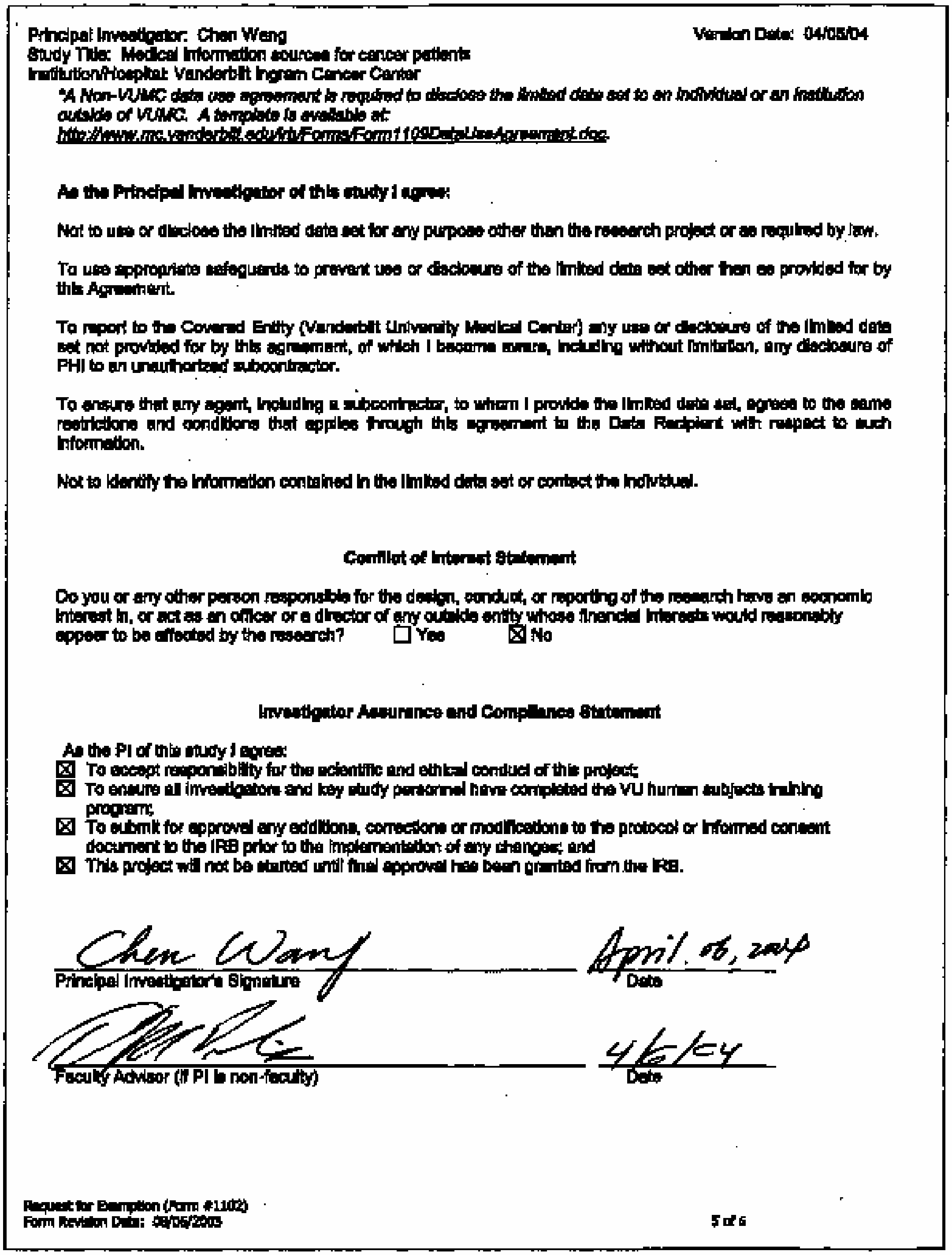
B. Will a limited data set be created?
☐ No ☐ Yes *If "Yes", complete the VUMC "Data Use Agreement" below.*

The data use agreement below sets forth the terms and conditions in which the Covered Entity (VUMC) will allow the use and disclosure of a limited data set [2] to the Data Recipient (Principal Investigator). The limited data set must have direct identifiers removed, but may include town, city, and/or 5-digit ZIP codes as well as data elements (e.g., dates of birth, admission, discharge, etc.).

VUMC DATA USE AGREEMENT ☐ **NOT APPLICABLE**

In addition to the Principal Investigator, identify all individuals who will be requesting authorization to access the limited data set:

Name of Institution and/or Individual	Non-VUMC Data Use Agreement Required?"
	☐ Yes ☐ No
	☐ Yes ☐ No
	☐ Yes ☐ No
	☐ Yes ☐ No
	☐ Yes ☐ No
	☐ Yes ☐ No



Principal Investigator: Chen Weng **Version Date:** 04/05/04
Study Title: Medical information sources for cancer patients
Institution/Hospital: Vanderbilt Ingram Cancer Center

**A Non-VUMC data use agreement is required to disclose the limited data set to an individual or an institution outside of VUMC. A template is available at: http://www.mc.vanderbilt.edu/irb/Forms/Form1109DataUseAgreement.doc.*

As the Principal Investigator of this study I agree:

Not to use or disclose the limited data set for any purpose other than the research project or as required by law.

To use appropriate safeguards to prevent use or disclosure of the limited data set other than as provided for by this Agreement.

To report to the Covered Entity (Vanderbilt University Medical Center) any use or disclosure of the limited data set not provided for by this agreement, of which I become aware, including without limitation, any disclosure of PHI to an unauthorized subcontractor.

To ensure that any agent, including a subcontractor, to whom I provide the limited data set, agrees to the same restrictions and conditions that applies through this agreement to the Data Recipient with respect to such information.

Not to identify the information contained in the limited data set or contact the individual.

Conflict of Interest Statement

Do you or any other person responsible for the design, conduct, or reporting of the research have an economic interest in, or act as an officer or a director of any outside entity whose financial interests would reasonably appear to be affected by the research? ☐ Yes ☒ No

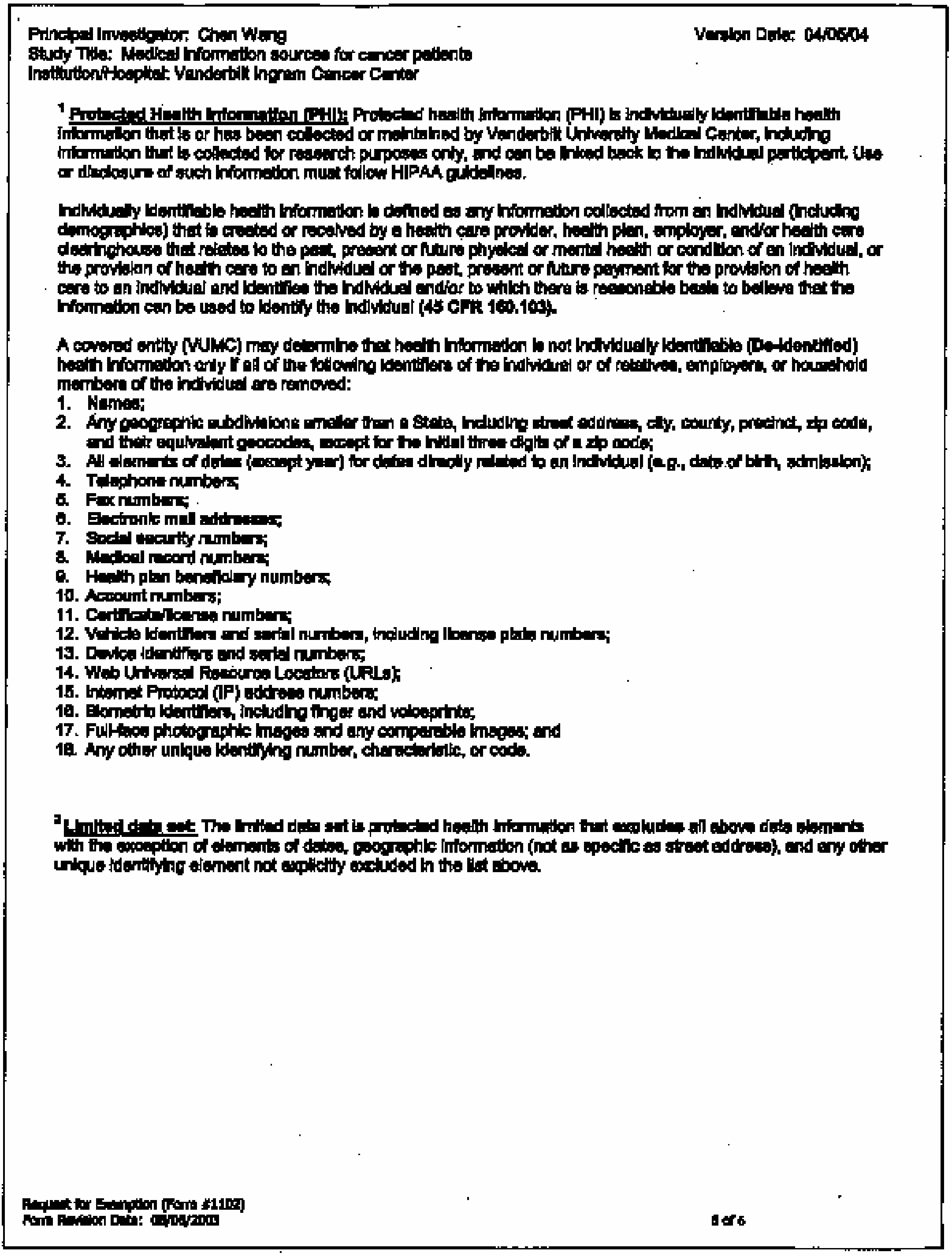
Investigator Assurance and Compliance Statement

As the PI of this study I agree:
☒ To accept responsibility for the scientific and ethical conduct of this project;
☒ To ensure all investigators and key study personnel have completed the VU human subjects training program;
☒ To submit for approval any additions, corrections or modifications to the protocol or informed consent document to the IRB prior to the implementation of any changes; and
☒ This project will not be started until final approval has been granted from the IRB.

Chen Wang April. 06, 2004
Principal Investigator's Signature Date

4/6/04
Faculty Advisor (If PI is non-faculty) Date

Request for Exemption (Form #1102)
Form Revision Date: 08/05/2003 5 of 6



[1] **Protected Health Information (PHI):** Protected health information (PHI) is individually identifiable health information that is or has been collected or maintained by Vanderbilt University Medical Center, including information that is collected for research purposes only, and can be linked back to the individual participant. Use or disclosure of such information must follow HIPAA guidelines.

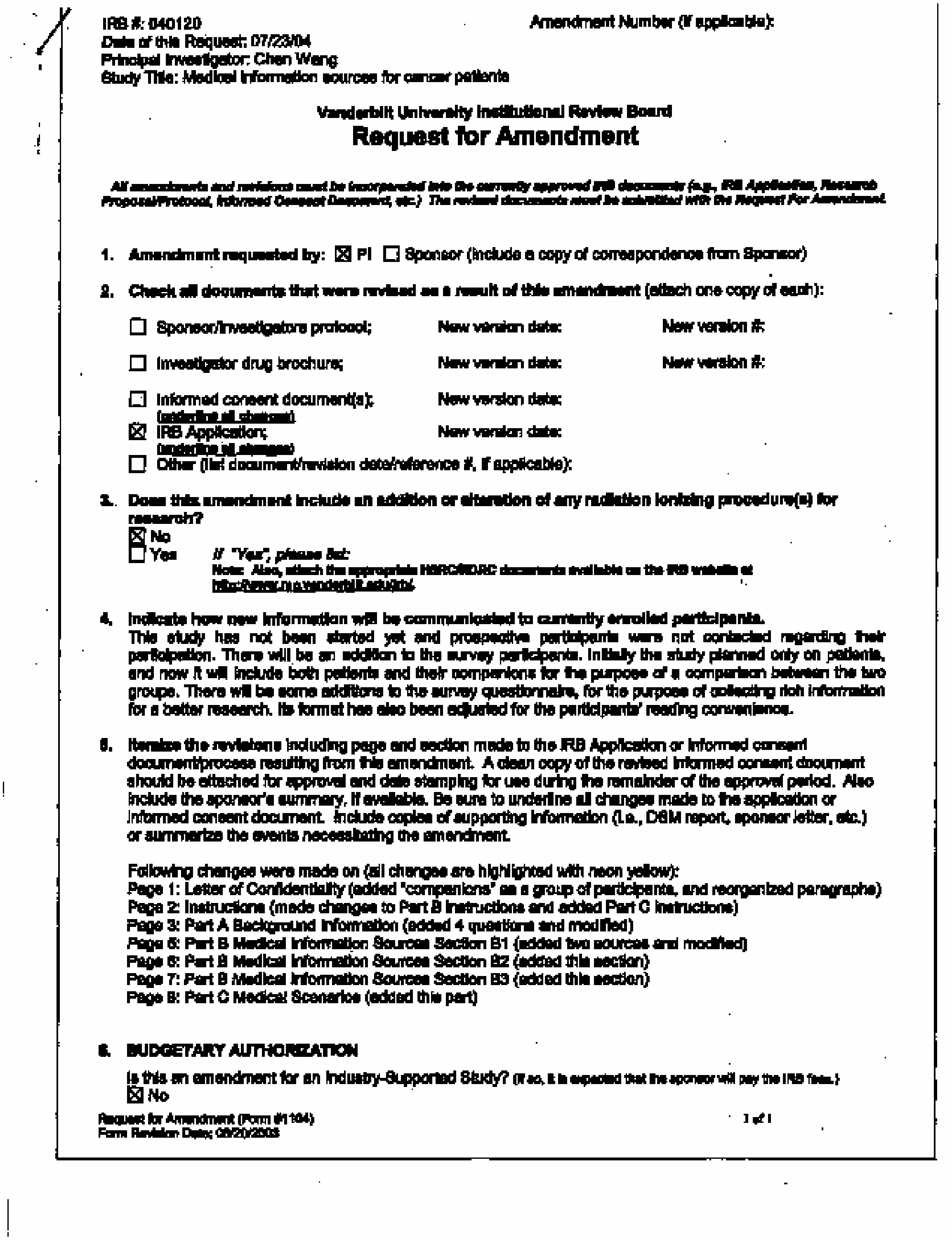
Individually identifiable health information is defined as any information collected from an individual (including demographics) that is created or received by a health care provider, health plan, employer, and/or health care clearinghouse that relates to the past, present or future physical or mental health or condition of an individual, or the provision of health care to an individual or the past, present or future payment for the provision of health care to an individual and identifies the individual and/or to which there is reasonable basis to believe that the information can be used to identify the individual (45 CFR 160.103).

A covered entity (VUMC) may determine that health information is not individually identifiable (De-identified) health information only if all of the following identifiers of the individual or of relatives, employers, or household members of the individual are removed:

1. Names;
2. Any geographic subdivisions smaller than a State, including street address, city, county, precinct, zip code, and their equivalent geocodes, except for the initial three digits of a zip code;
3. All elements of dates (except year) for dates directly related to an individual (e.g., date of birth, admission);
4. Telephone numbers;
5. Fax numbers;
6. Electronic mail addresses;
7. Social security numbers;
8. Medical record numbers;
9. Health plan beneficiary numbers;
10. Account numbers;
11. Certificate/license numbers;
12. Vehicle identifiers and serial numbers, including license plate numbers;
13. Device identifiers and serial numbers;
14. Web Universal Resource Locators (URLs);
15. Internet Protocol (IP) address numbers;
16. Biometric identifiers, including finger and voiceprints;
17. Full-face photographic images and any comparable images; and
18. Any other unique identifying number, characteristic, or code.

[2] **Limited data set:** The limited data set is protected health information that excludes all above data elements with the exception of elements of dates, geographic information (not as specific as street address), and any other unique identifying element not explicitly excluded in the list above.

July 23, 2004



IRB #: 040120
Date of this Request: 07/23/04
Principal Investigator: Chen Wang
Study Title: Medical information sources for cancer patients

Amendment Number (if applicable):

Vanderbilt University Institutional Review Board

Request for Amendment

All amendments and revisions must be incorporated into the currently approved IRB documents (e.g., IRB Application, Research Proposal/Protocol, Informed Consent Document, etc.) The revised documents must be submitted with the Request For Amendment.

1. **Amendment requested by:** ☒ PI ☐ Sponsor (include a copy of correspondence from Sponsor)

2. **Check all documents that were revised as a result of this amendment** (attach one copy of each):

☐ Sponsor/investigators protocol;	New version date:	New version #:
☐ Investigator drug brochure;	New version date:	New version #:
☐ Informed consent document(s); (underline all changes)	New version date:	
☒ IRB Application; (underline all changes)	New version date:	
☐ Other (list document/revision date/reference #, if applicable):		

3. **Does this amendment include an addition or alteration of any radiation ionizing procedure(s) for research?**
☒ No
☐ Yes *If "Yes", please list:*
Note: Also, attach the appropriate HSRC/RDRC documents available on the IRB website at http://www.mc.vanderbilt.edu/irb/

4. **Indicate how new information will be communicated to currently enrolled participants.**
This study has not been started yet and prospective participants were not contacted regarding their participation. There will be an addition to the survey participants. Initially the study planned only on patients, and now it will include both patients and their companions for the purpose of a comparison between the two groups. There will be some additions to the survey questionnaire, for the purpose of collecting rich information for a better research. Its format has also been adjusted for the participants' reading convenience.

5. **Itemize the revisions including page and section made to the IRB Application or informed consent document/process resulting from this amendment. A clean copy of the revised informed consent document should be attached for approval and date stamping for use during the remainder of the approval period. Also include the sponsor's summary, if available. Be sure to underline all changes made to the application or informed consent document. Include copies of supporting information (i.e., DSM report, sponsor letter, etc.) or summarize the events necessitating the amendment.**

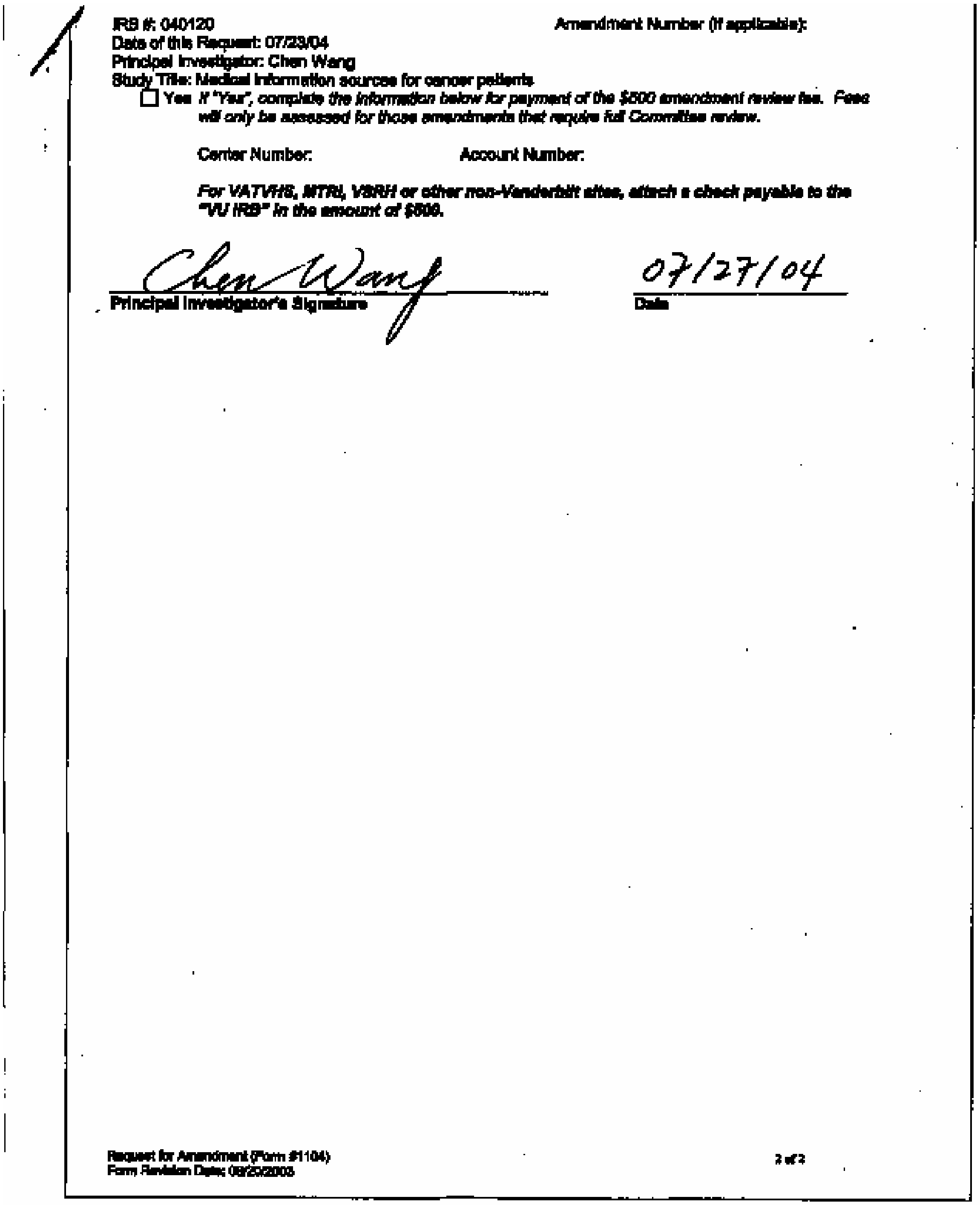
Following changes were made on (all changes are highlighted with neon yellow):
Page 1: Letter of Confidentiality (added "companions" as a group of participants, and reorganized paragraphs)
Page 2: Instructions (made changes to Part B instructions and added Part C instructions)
Page 3: Part A Background Information (added 4 questions and modified)
Page 5: Part B Medical Information Sources Section B1 (added two sources and modified)
Page 6: Part B Medical Information Sources Section B2 (added this section)
Page 7: Part B Medical Information Sources Section B3 (added this section)
Page 8: Part C Medical Scenarios (added this part)

6. **BUDGETARY AUTHORIZATION**

Is this an amendment for an Industry-Supported Study? (If so, it is expected that the sponsor will pay the IRB fees.)
☒ No

Request for Amendment (Form #1104)
Form Revision Date: 08/20/2003

1 of 1



IRB #: 040120 **Amendment Number (if applicable):**
Date of this Request: 07/23/04
Principal Investigator: Chen Wang
Study Title: Medical information sources for cancer patients

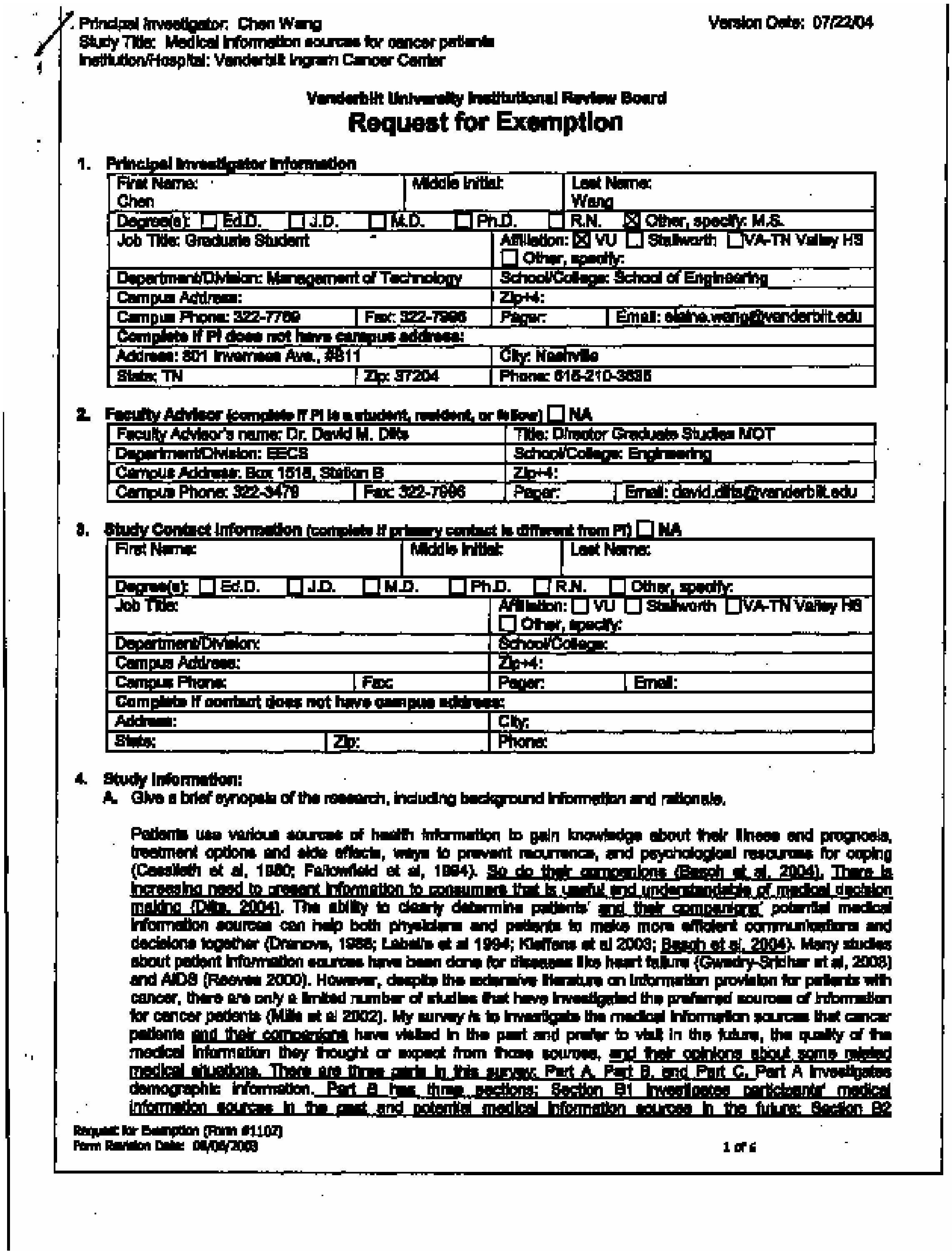
☐ **Yes** ***If "Yes", complete the information below for payment of the $500 amendment review fee. Fees will only be assessed for those amendments that require full Committee review.***

Center Number: **Account Number:**

For VATVHS, MTRI, VSRH or other non-Vanderbilt sites, attach a check payable to the "VU IRB" in the amount of $500.

Chen Wang 07/27/04
Principal Investigator's Signature **Date**

Request for Amendment (Form #1104)
Form Revision Date: 08/20/2003
2 of 2



Principal Investigator: Chen Wang
Study Title: Medical information sources for cancer patients
Institution/Hospital: Vanderbilt Ingram Cancer Center

Version Date: 07/22/04

Vanderbilt University Institutional Review Board

Request for Exemption

1. **Principal Investigator Information**

First Name: Chen | Middle Initial: | Last Name: Wang
Degree(s): ☐ Ed.D. ☐ J.D. ☐ M.D. ☐ Ph.D. ☐ R.N. ☒ Other, specify: M.S.
Job Title: Graduate Student | Affiliation: ☒ VU ☐ Stallworth ☐ VA-TN Valley HS ☐ Other, specify:
Department/Division: Management of Technology | School/College: School of Engineering
Campus Address: | Zip+4:
Campus Phone: 322-7769 | Fax: 322-7996 | Pager: | Email: elaine.wang@vanderbilt.edu
Complete if PI does not have campus address:
Address: 801 Inverness Ave., #811 | City: Nashville
State: TN | Zip: 37204 | Phone: 615-210-3635

2. **Faculty Advisor** (complete if PI is a student, resident, or fellow) ☐ NA

Faculty Advisor's name: Dr. David M. Dilts | Title: Director Graduate Studies MOT
Department/Division: EECS | School/College: Engineering
Campus Address: Box 1518, Station B | Zip+4:
Campus Phone: 322-3479 | Fax: 322-7996 | Pager: | Email: david.dilts@vanderbilt.edu

3. **Study Contact Information** (complete if primary contact is different from PI) ☐ NA

First Name: | Middle Initial: | Last Name:
Degree(s): ☐ Ed.D. ☐ J.D. ☐ M.D. ☐ Ph.D. ☐ R.N. ☐ Other, specify:
Job Title: | Affiliation: ☐ VU ☐ Stallworth ☐ VA-TN Valley HS ☐ Other, specify:
Department/Division: | School/College:
Campus Address: | Zip+4:
Campus Phone: | Fax: | Pager: | Email:
Complete if contact does not have campus address:
Address: | City:
State: | Zip: | Phone:

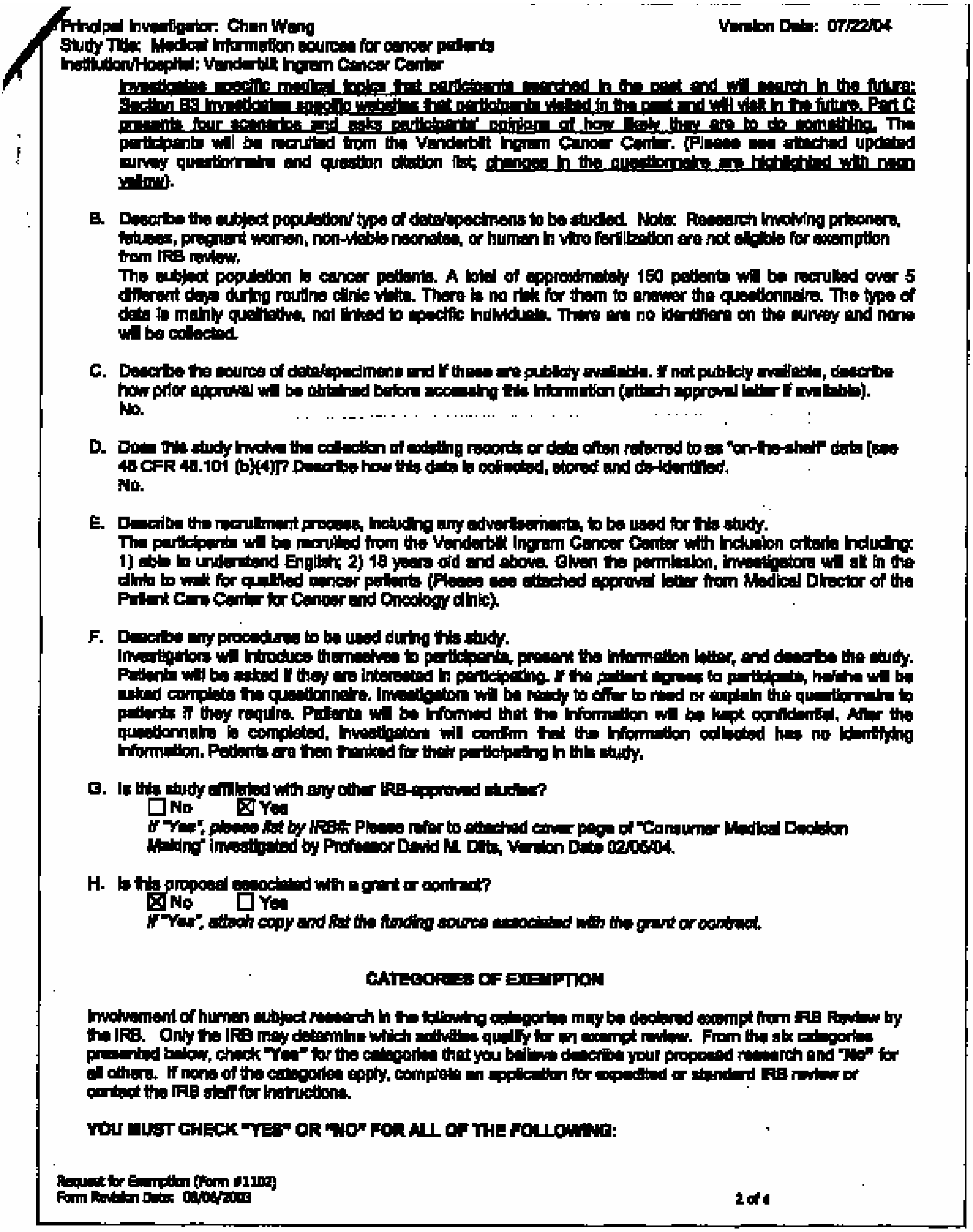
4. **Study Information:**

   A. Give a brief synopsis of the research, including background information and rationale.

Patients use various sources of health information to gain knowledge about their illness and prognosis, treatment options and side effects, ways to prevent recurrence, and psychological resources for coping (Cassileth et al, 1980; Fallowfield et al, 1994). So do their companions (Beach et al, 2004). There is increasing need to present information to consumers that is useful and understandable of medical decision making (Dilts, 2004). The ability to clearly determine patients' and their companions' potential medical information sources can help both physicians and patients to make more efficient communications and decisions together (Dranove, 1988; Labelle et al 1994; Kleffens et al 2003; Beach et al, 2004). Many studies about patient information sources have been done for diseases like heart failure (Gwadry-Sridhar et al, 2003) and AIDS (Reeves 2000). However, despite the extensive literature on information provision for patients with cancer, there are only a limited number of studies that have investigated the preferred sources of information for cancer patients (Mills et al 2002). My survey is to investigate the medical information sources that cancer patients and their companions have visited in the past and prefer to visit in the future, the quality of the medical information they thought or expect from those sources, and their opinions about some related medical situations. There are three parts in this survey: Part A, Part B, and Part C. Part A investigates demographic information. Part B has three sections: Section B1 investigates participants' medical information sources in the past and potential medical information sources in the future; Section B2

Request for Exemption (Form #1107)
Form Revision Date: 06/06/2003

1 of 6



Principal Investigator: Chen Wang Version Date: 07/22/04
Study Title: Medical information sources for cancer patients
Institution/Hospital: Vanderbilt Ingram Cancer Center

investigates specific medical topics that participants searched in the past and will search in the future; Section B3 investigates specific websites that participants visited in the past and will visit in the future. Part C presents four scenarios and asks participants' opinions of how likely they are to do something. The participants will be recruited from the Vanderbilt Ingram Cancer Center. (Please see attached updated survey questionnaire and question citation list; changes in the questionnaire are highlighted with neon yellow).

B. Describe the subject population/ type of data/specimens to be studied. Note: Research involving prisoners, fetuses, pregnant women, non-viable neonates, or human in vitro fertilization are not eligible for exemption from IRB review.
The subject population is cancer patients. A total of approximately 150 patients will be recruited over 5 different days during routine clinic visits. There is no risk for them to answer the questionnaire. The type of data is mainly qualitative, not linked to specific individuals. There are no identifiers on the survey and none will be collected.

C. Describe the source of data/specimens and if these are publicly available. If not publicly available, describe how prior approval will be obtained before accessing this information (attach approval letter if available).
No.

D. Does this study involve the collection of existing records or data often referred to as "on-the-shelf" data [see 45 CFR 46.101 (b)(4)]? Describe how this data is collected, stored and de-identified.
No.

E. Describe the recruitment process, including any advertisements, to be used for this study.
The participants will be recruited from the Vanderbilt Ingram Cancer Center with inclusion criteria including: 1) able to understand English; 2) 18 years old and above. Given the permission, investigators will sit in the clinic to wait for qualified cancer patients (Please see attached approval letter from Medical Director of the Patient Care Center for Cancer and Oncology clinic).

F. Describe any procedures to be used during this study.
Investigators will introduce themselves to participants, present the information letter, and describe the study. Patients will be asked if they are interested in participating. If the patient agrees to participate, he/she will be asked complete the questionnaire. Investigators will be ready to offer to read or explain the questionnaire to patients if they require. Patients will be informed that the information will be kept confidential. After the questionnaire is completed, investigators will confirm that the information collected has no identifying information. Patients are then thanked for their participating in this study.

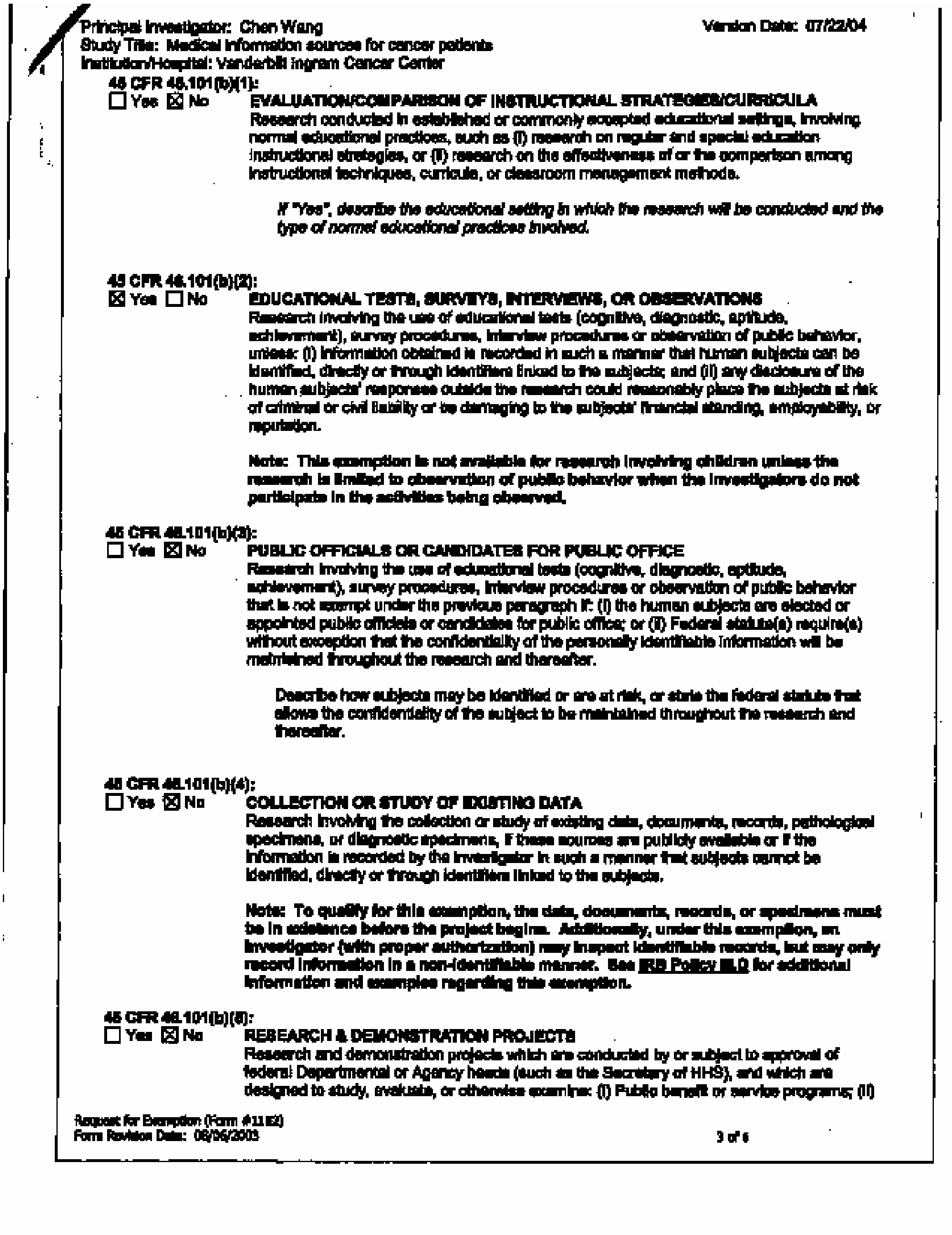
G. Is this study affiliated with any other IRB-approved studies?
☐ No ☒ Yes
If "Yes", please list by IRB#: Please refer to attached cover page of "Consumer Medical Decision Making" investigated by Professor David M. Dilts, Version Date 02/06/04.

H. Is this proposal associated with a grant or contract?
☒ No ☐ Yes
If "Yes", attach copy and list the funding source associated with the grant or contract.

CATEGORIES OF EXEMPTION

Involvement of human subject research in the following categories may be declared exempt from IRB Review by the IRB. Only the IRB may determine which activities qualify for an exempt review. From the six categories presented below, check "Yes" for the categories that you believe describe your proposed research and "No" for all others. If none of the categories apply, complete an application for expedited or standard IRB review or contact the IRB staff for instructions.

YOU MUST CHECK "YES" OR "NO" FOR ALL OF THE FOLLOWING:



Principal Investigator: Chen Wang
Version Date: 07/22/04
Study Title: Medical information sources for cancer patients
Institution/Hospital: Vanderbilt Ingram Cancer Center

45 CFR 46.101(b)(1):
☐ Yes ☒ No **EVALUATION/COMPARISON OF INSTRUCTIONAL STRATEGIES/CURRICULA**
Research conducted in established or commonly accepted educational settings, involving normal educational practices, such as (i) research on regular and special education instructional strategies, or (ii) research on the effectiveness of or the comparison among instructional techniques, curricula, or classroom management methods.

If "Yes", describe the educational setting in which the research will be conducted and the type of normal educational practices involved.

45 CFR 46.101(b)(2):
☒ Yes ☐ No **EDUCATIONAL TESTS, SURVEYS, INTERVIEWS, OR OBSERVATIONS**
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.

Note: This exemption is not available for research involving children unless the research is limited to observation of public behavior when the investigators do not participate in the activities being observed.

45 CFR 46.101(b)(3):
☐ Yes ☒ No **PUBLIC OFFICIALS OR CANDIDATES FOR PUBLIC OFFICE**
Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior that is not exempt under the previous paragraph if: (i) the human subjects are elected or appointed public officials or candidates for public office; or (ii) Federal statute(s) require(s) without exception that the confidentiality of the personally identifiable information will be maintained throughout the research and thereafter.

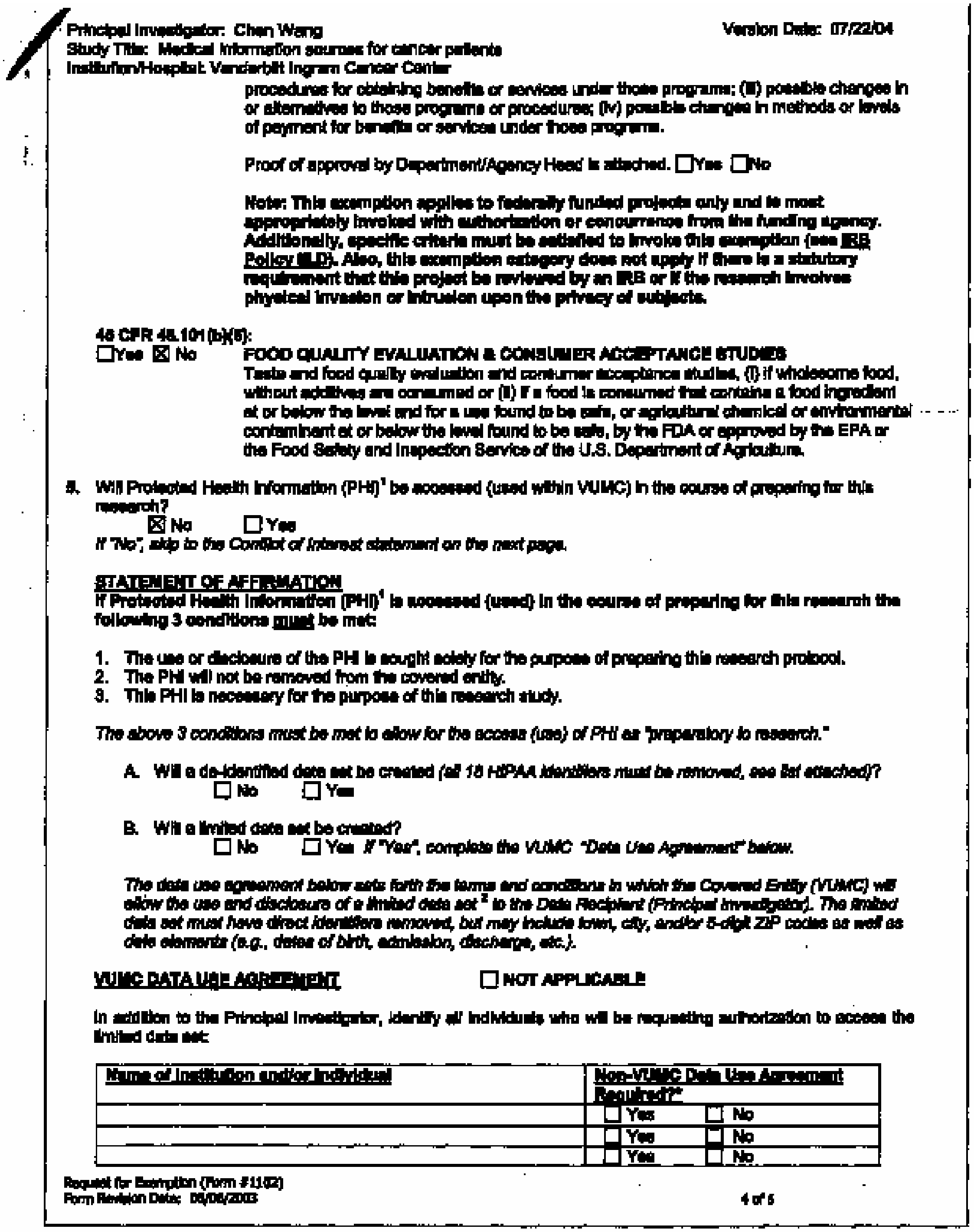
Describe how subjects may be identified or are at risk, or state the federal statute that allows the confidentiality of the subject to be maintained throughout the research and thereafter.

45 CFR 46.101(b)(4):
☐ Yes ☒ No **COLLECTION OR STUDY OF EXISTING DATA**
Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these sources are publicly available or if the information is recorded by the investigator in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects.

Note: To qualify for this exemption, the data, documents, records, or specimens must be in existence before the project begins. Additionally, under this exemption, an investigator (with proper authorization) may inspect identifiable records, but may only record information in a non-identifiable manner. See IRB Policy III.D for additional information and examples regarding this exemption.

45 CFR 46.101(b)(5):
☐ Yes ☒ No **RESEARCH & DEMONSTRATION PROJECTS**
Research and demonstration projects which are conducted by or subject to approval of federal Departmental or Agency heads (such as the Secretary of HHS), and which are designed to study, evaluate, or otherwise examine: (i) Public benefit or service programs; (ii)

Request for Exemption (Form #11EX)
Form Revision Date: 06/06/2003
3 of 6



procedures for obtaining benefits or services under those programs; (iii) possible changes in or alternatives to those programs or procedures; (iv) possible changes in methods or levels of payment for benefits or services under those programs.

Proof of approval by Department/Agency Head is attached. ☐Yes ☐No

Note: This exemption applies to federally funded projects only and is most appropriately invoked with authorization or concurrence from the funding agency. Additionally, specific criteria must be satisfied to invoke this exemption (see <u>IRB Policy III.D</u>). Also, this exemption category does not apply if there is a statutory requirement that this project be reviewed by an IRB or if the research involves physical invasion or intrusion upon the privacy of subjects.

45 CFR 46.101(b)(6):
☐Yes ☒ No **FOOD QUALITY EVALUATION & CONSUMER ACCEPTANCE STUDIES**
Taste and food quality evaluation and consumer acceptance studies, (i) if wholesome food, without additives are consumed or (ii) if a food is consumed that contains a food ingredient at or below the level and for a use found to be safe, or agricultural chemical or environmental contaminant at or below the level found to be safe, by the FDA or approved by the EPA or the Food Safety and Inspection Service of the U.S. Department of Agriculture.

5. Will Protected Health Information (PHI)[1] be accessed (used within VUMC) in the course of preparing for this research?
☒ No ☐ Yes
If "No", skip to the Conflict of Interest statement on the next page.

<u>STATEMENT OF AFFIRMATION</u>
If Protected Health Information (PHI)[1] is accessed (used) in the course of preparing for this research the following 3 conditions <u>must</u> be met:

1. The use or disclosure of the PHI is sought solely for the purpose of preparing this research protocol.
2. The PHI will not be removed from the covered entity.
3. This PHI is necessary for the purpose of this research study.

The above 3 conditions must be met to allow for the access (use) of PHI as "preparatory to research."

A. Will a de-identified data set be created *(all 18 HIPAA identifiers must be removed, see list attached)*?
☐ No ☐ Yes

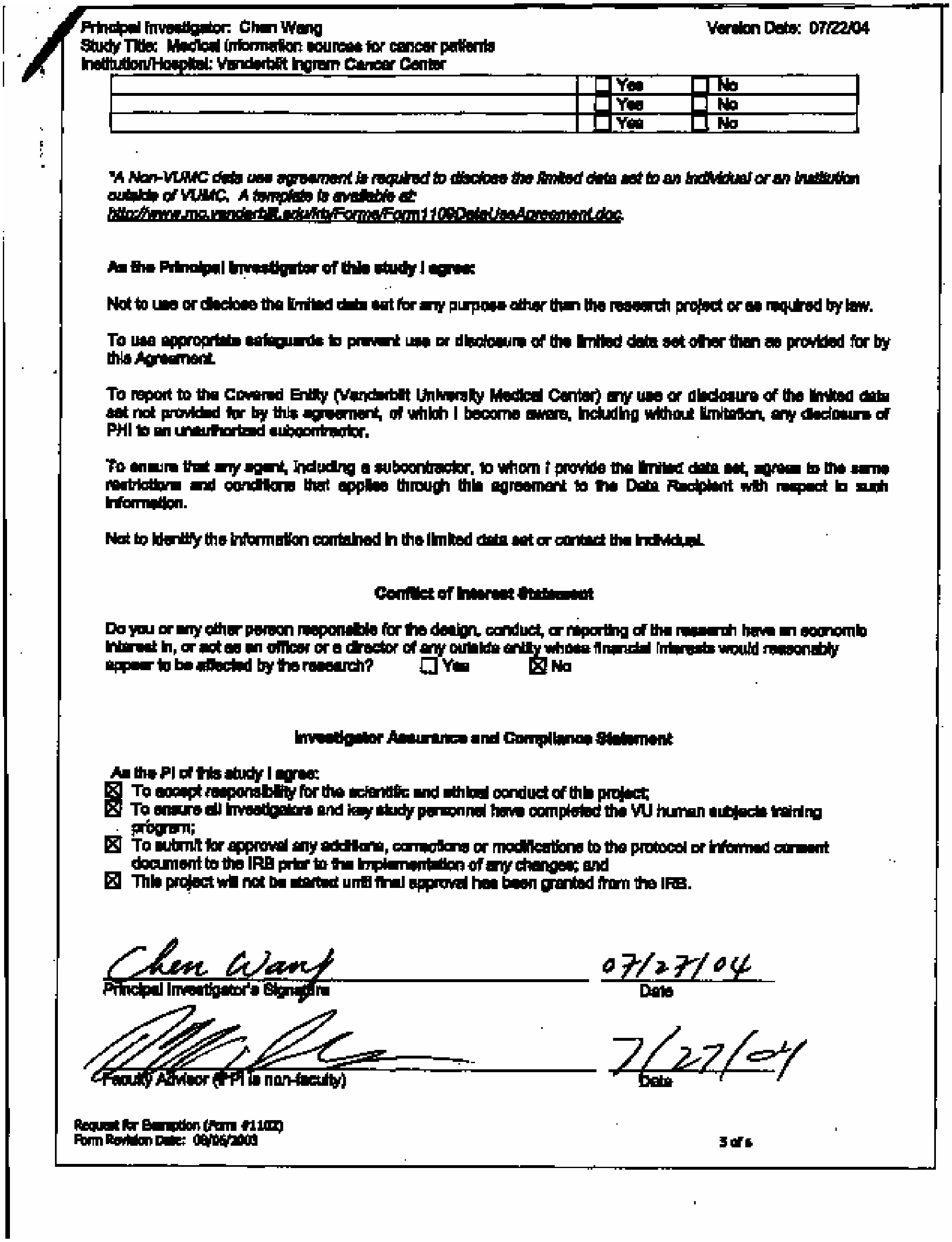
B. Will a limited data set be created?
☐ No ☐ Yes *If "Yes", complete the VUMC "Data Use Agreement" below.*

The data use agreement below sets forth the terms and conditions in which the Covered Entity (VUMC) will allow the use and disclosure of a limited data set [2] to the Data Recipient (Principal Investigator). The limited data set must have direct identifiers removed, but may include town, city, and/or 5-digit ZIP codes as well as data elements (e.g., dates of birth, admission, discharge, etc.).

<u>VUMC DATA USE AGREEMENT</u> ☐ **NOT APPLICABLE**

In addition to the Principal Investigator, identify *all* individuals who will be requesting authorization to access the limited data set:

<u>Name of Institution and/or Individual</u>	<u>Non-VUMC Data Use Agreement Required?*</u>
	☐ Yes ☐ No
	☐ Yes ☐ No
	☐ Yes ☐ No



Principal Investigator: Chen Wang **Version Date:** 07/22/04
Study Title: Medical information sources for cancer patients
Institution/Hospital: Vanderbilt Ingram Cancer Center

	☐ Yes ☐ No
	☐ Yes ☐ No
	☐ Yes ☐ No

*A Non-VUMC data use agreement is required to disclose the limited data set to an individual or an institution outside of VUMC. A template is available at: http://www.mc.vanderbilt.edu/irb/Forms/Form1109DataUseAgreement.doc.

As the Principal Investigator of this study I agree:

Not to use or disclose the limited data set for any purpose other than the research project or as required by law.

To use appropriate safeguards to prevent use or disclosure of the limited data set other than as provided for by this Agreement.

To report to the Covered Entity (Vanderbilt University Medical Center) any use or disclosure of the limited data set not provided for by this agreement, of which I become aware, including without limitation, any disclosure of PHI to an unauthorized subcontractor.

To ensure that any agent, including a subcontractor, to whom I provide the limited data set, agrees to the same restrictions and conditions that applies through this agreement to the Data Recipient with respect to such information.

Not to identify the information contained in the limited data set or contact the individual.

Conflict of Interest Statement

Do you or any other person responsible for the design, conduct, or reporting of the research have an economic interest in, or act as an officer or a director of any outside entity whose financial interests would reasonably appear to be affected by the research? ☐ Yes ☒ No

Investigator Assurance and Compliance Statement

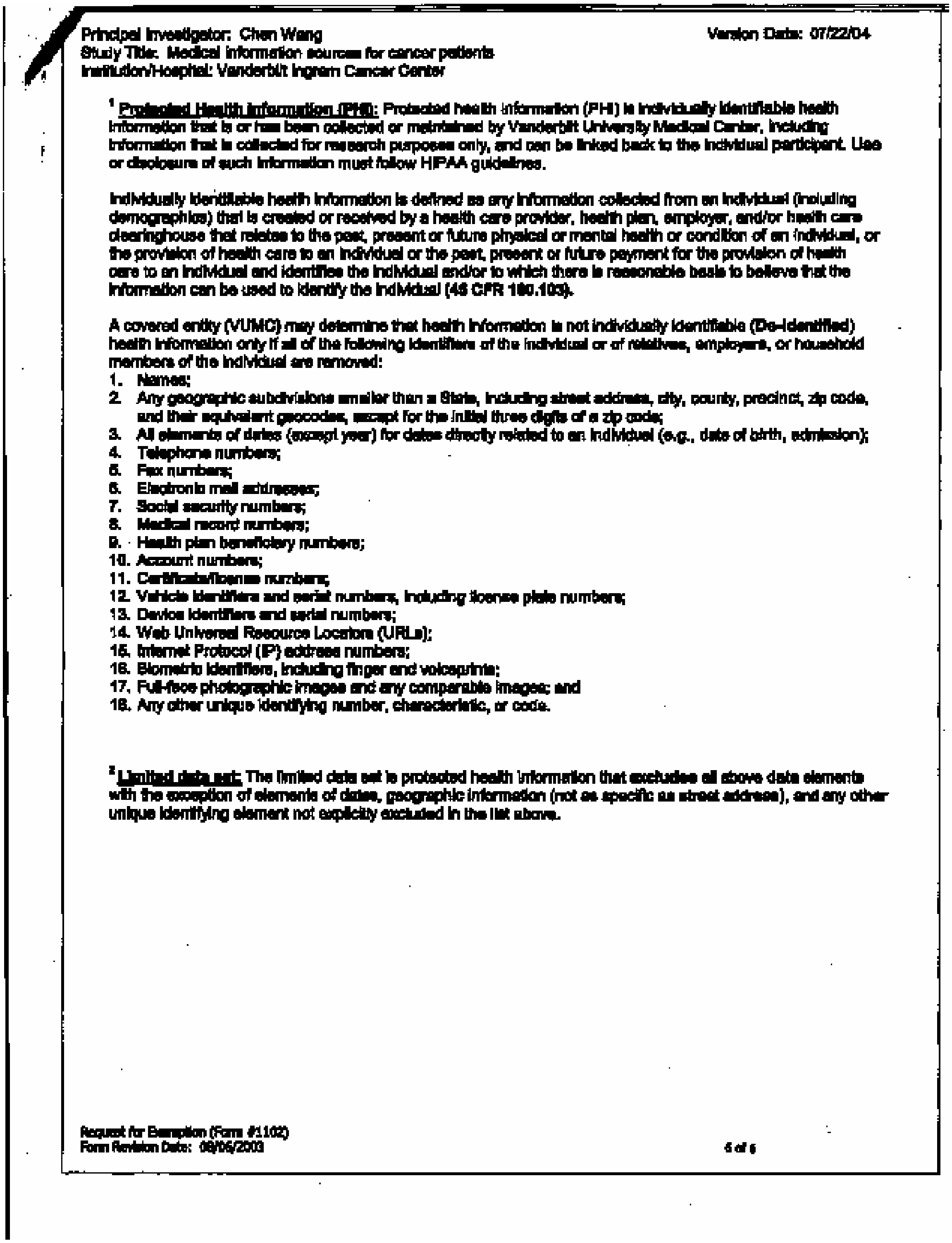
As the PI of this study I agree:

- ☒ To accept responsibility for the scientific and ethical conduct of this project;
- ☒ To ensure all investigators and key study personnel have completed the VU human subjects training program;
- ☒ To submit for approval any additions, corrections or modifications to the protocol or informed consent document to the IRB prior to the implementation of any changes; and
- ☒ This project will not be started until final approval has been granted from the IRB.

Chen Wang 07/27/04
Principal Investigator's Signature Date

7/27/04
Faculty Advisor (if PI is non-faculty) Date

Request for Exemption (Form #1102)
Form Revision Date: 08/06/2003 3 of 6



Principal Investigator: Chen Wang
Study Title: Medical information sources for cancer patients
Institution/Hospital: Vanderbilt Ingram Cancer Center

Version Date: 07/22/04

[1] Protected Health Information (PHI): Protected health information (PHI) is individually identifiable health information that is or has been collected or maintained by Vanderbilt University Medical Center, including information that is collected for research purposes only, and can be linked back to the individual participant. Use or disclosure of such information must follow HIPAA guidelines.

Individually identifiable health information is defined as any information collected from an individual (including demographics) that is created or received by a health care provider, health plan, employer, and/or health care clearinghouse that relates to the past, present or future physical or mental health or condition of an individual, or the provision of health care to an individual or the past, present or future payment for the provision of health care to an individual and identifies the individual and/or to which there is reasonable basis to believe that the information can be used to identify the individual (45 CFR 160.103).

A covered entity (VUMC) may determine that health information is not individually identifiable (De-identified) health information only if all of the following identifiers of the individual or of relatives, employers, or household members of the individual are removed:

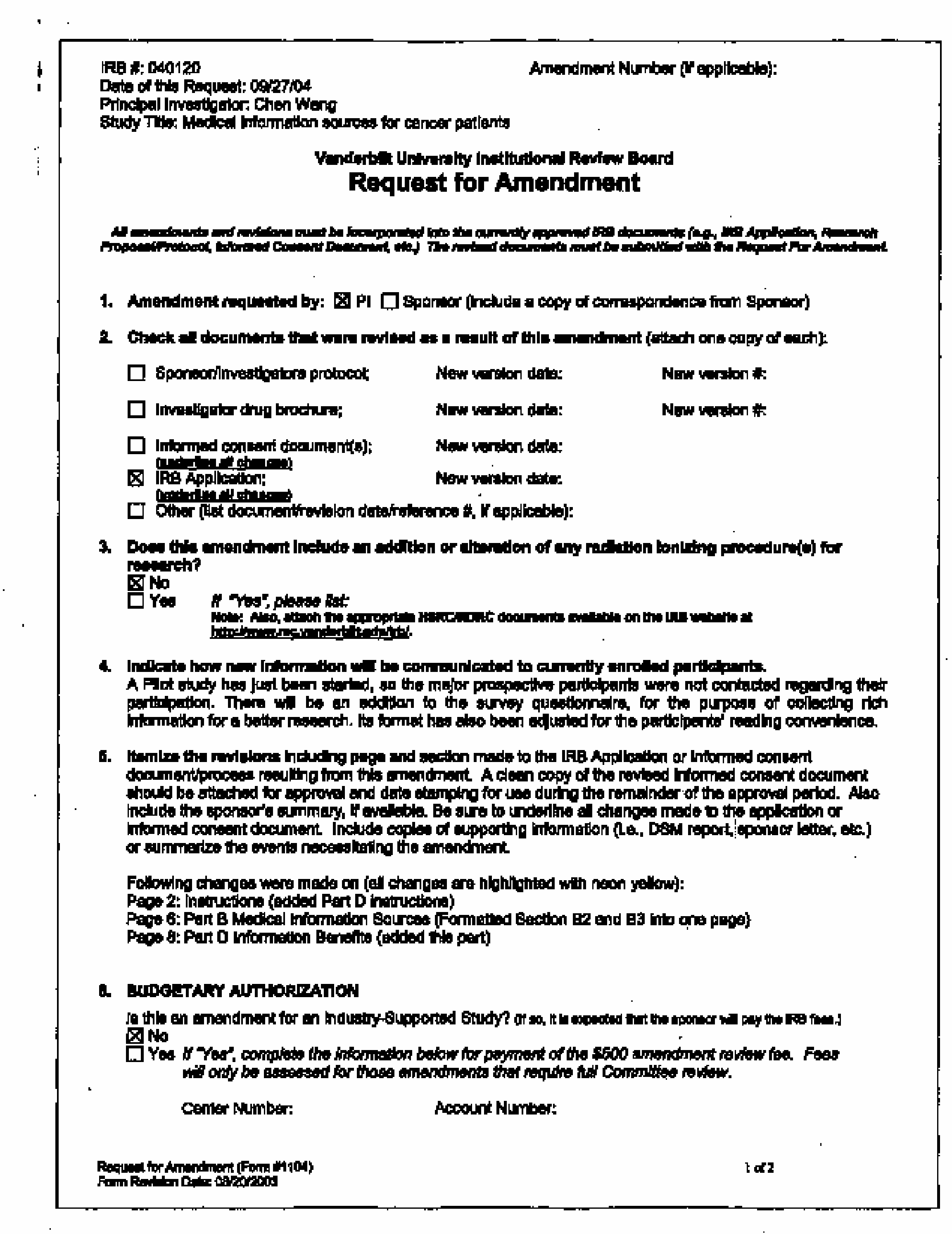
1. Names;
2. Any geographic subdivisions smaller than a State, including street address, city, county, precinct, zip code, and their equivalent geocodes, except for the initial three digits of a zip code;
3. All elements of dates (except year) for dates directly related to an individual (e.g., date of birth, admission);
4. Telephone numbers;
5. Fax numbers;
6. Electronic mail addresses;
7. Social security numbers;
8. Medical record numbers;
9. Health plan beneficiary numbers;
10. Account numbers;
11. Certificate/license numbers;
12. Vehicle identifiers and serial numbers, including license plate numbers;
13. Device identifiers and serial numbers;
14. Web Universal Resource Locators (URLs);
15. Internet Protocol (IP) address numbers;
16. Biometric identifiers, including finger and voiceprints;
17. Full-face photographic images and any comparable images; and
18. Any other unique identifying number, characteristic, or code.

[2] Limited data set: The limited data set is protected health information that excludes all above data elements with the exception of elements of dates, geographic information (not as specific as street address), and any other unique identifying element not explicitly excluded in the list above.

Request for Exemption (Form #1102)
Form Revision Date: 08/06/2003

6 of 6

September 27, 2004



IRB #: 040120 Amendment Number (if applicable):
Date of this Request: 09/27/04
Principal Investigator: Chen Wang
Study Title: Medical information sources for cancer patients

Vanderbilt University Institutional Review Board

Request for Amendment

All amendments and revisions must be incorporated into the currently approved IRB documents (e.g., IRB Application, Research Proposal/Protocol, Informed Consent Document, etc.) The revised documents must be submitted with the Request For Amendment.

1. **Amendment requested by:** ☒ PI ☐ Sponsor (include a copy of correspondence from Sponsor)

2. **Check all documents that were revised as a result of this amendment (attach one copy of each):**

☐ Sponsor/investigators protocol;	New version date:	New version #:
☐ Investigator drug brochure;	New version date:	New version #:
☐ Informed consent document(s); (underline all changes)	New version date:	
☒ IRB Application; (underline all changes)	New version date:	

☐ Other (list document/revision date/reference #, if applicable):

3. **Does this amendment include an addition or alteration of any radiation ionizing procedure(s) for research?**
☒ No
☐ Yes *If "Yes", please list:*
Note: Also, attach the appropriate RSC/RDRC documents available on the IRB website at http://www.mc.vanderbilt.edu/irb/.

4. **Indicate how new information will be communicated to currently enrolled participants.**
A Pilot study has just been started, so the major prospective participants were not contacted regarding their participation. There will be an addition to the survey questionnaire, for the purpose of collecting rich information for a better research. Its format has also been adjusted for the participants' reading convenience.

5. **Itemize the revisions including page and section made to the IRB Application or informed consent document/process resulting from this amendment. A clean copy of the revised informed consent document should be attached for approval and date stamping for use during the remainder of the approval period. Also include the sponsor's summary, if available. Be sure to underline all changes made to the application or informed consent document. Include copies of supporting information (i.e., DSM report, sponsor letter, etc.) or summarize the events necessitating the amendment.**

Following changes were made on (all changes are highlighted with neon yellow):
Page 2: Instructions (added Part D instructions)
Page 6: Part B Medical Information Sources (Formatted Section B2 and B3 into one page)
Page 8: Part D Information Benefits (added this part)

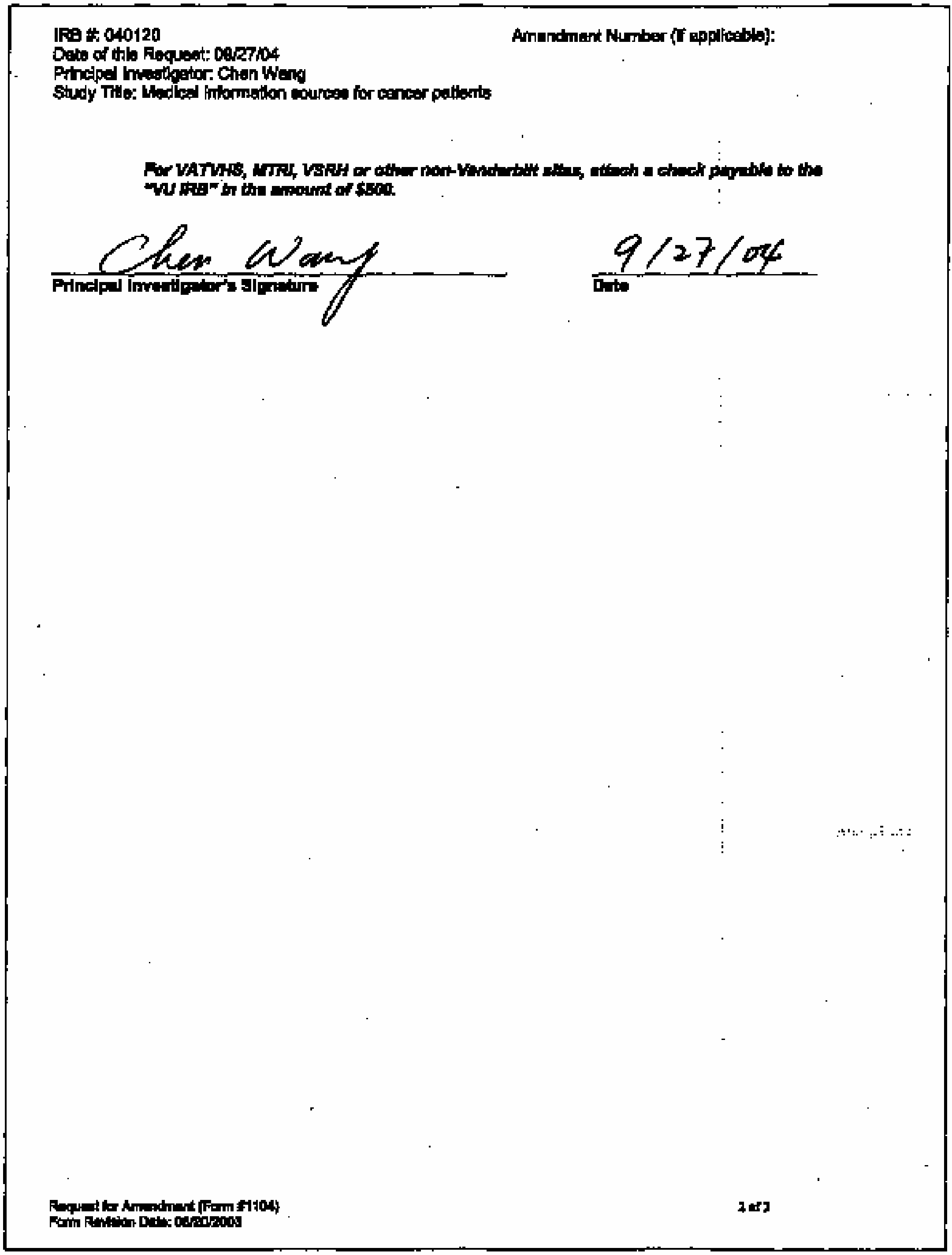
6. **BUDGETARY AUTHORIZATION**

Is this an amendment for an Industry-Supported Study? (If so, it is expected that the sponsor will pay the IRB fees.)
☒ No
☐ Yes *If "Yes", complete the information below for payment of the $500 amendment review fee. Fees will only be assessed for those amendments that require full Committee review.*

Center Number: Account Number:

Request for Amendment (Form #1104)
Form Revision Date: 03/20/2003

1 of 2



IRB #: 040120
Date of this Request: 09/27/04
Principal Investigator: Chen Wang
Study Title: Medical information sources for cancer patients

Amendment Number (if applicable):

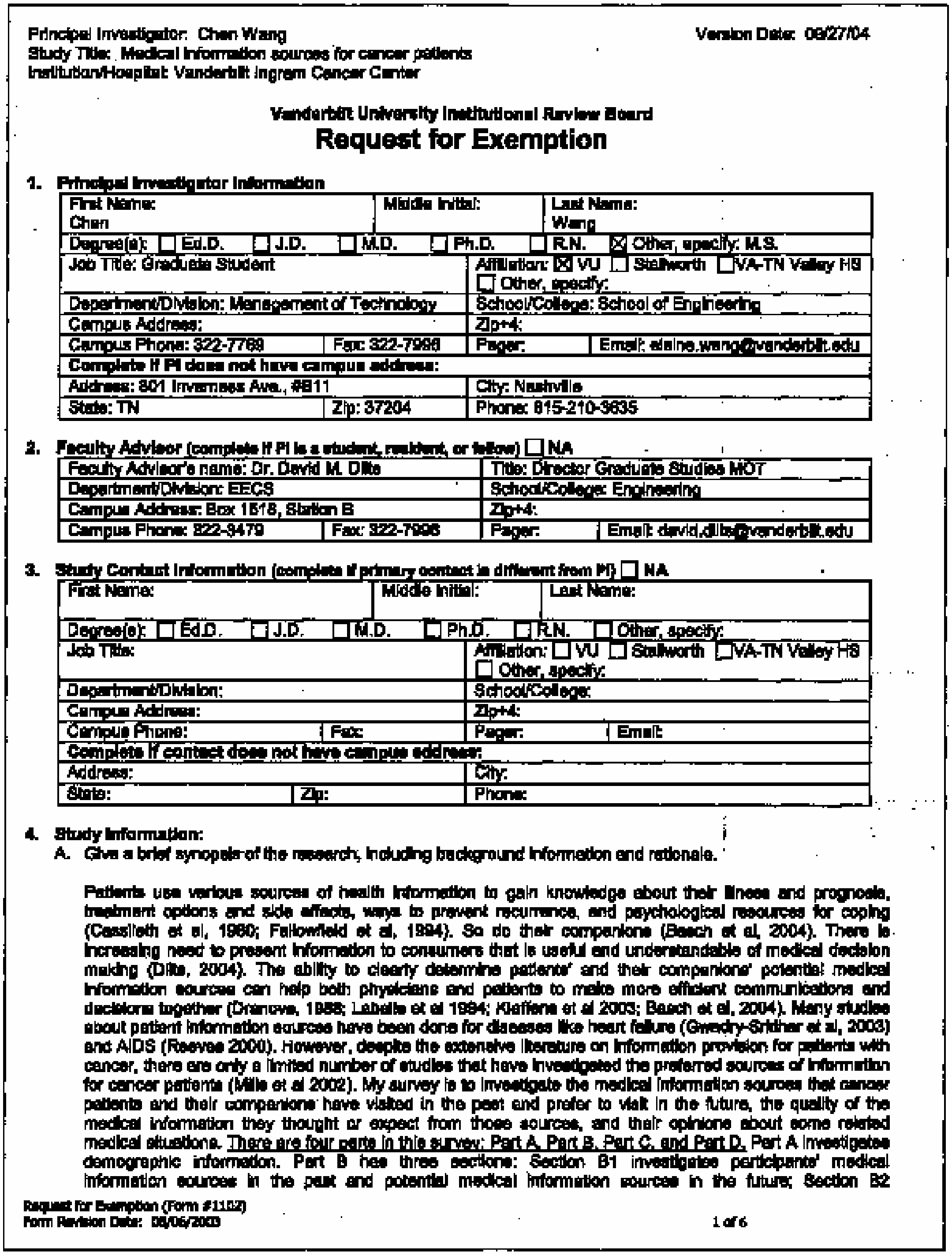
For VATVHS, MTRI, VSRH or other non-Vanderbilt sites, attach a check payable to the "VU IRB" in the amount of $500.

Chen Wang
Principal Investigator's Signature

9/27/04
Date

Request for Amendment (Form #1104)
Form Revision Date: 08/20/2003

2 of 2



Principal Investigator: Chen Wang
Study Title: Medical information sources for cancer patients
Institution/Hospital: Vanderbilt Ingram Cancer Center

Version Date: 09/27/04

Vanderbilt University Institutional Review Board

Request for Exemption

1. Principal Investigator Information

First Name: Chen	Middle Initial:	Last Name: Wang

Degree(s): ☐ Ed.D. ☐ J.D. ☐ M.D. ☐ Ph.D. ☐ R.N. ☒ Other, specify: M.S.

Job Title: Graduate Student		Affiliation: ☒ VU ☐ Stallworth ☐ VA-TN Valley HS ☐ Other, specify:	
Department/Division: Management of Technology		School/College: School of Engineering	
Campus Address:		Zip+4:	
Campus Phone: 322-7769	Fax: 322-7996	Pager:	Email: elaine.wang@vanderbilt.edu
Complete if PI does not have campus address:			
Address: 801 Inverness Ave., #811		City: Nashville	
State: TN	Zip: 37204	Phone: 615-210-3635	

2. Faculty Advisor (complete if PI is a student, resident, or fellow) ☐ NA

Faculty Advisor's name: Dr. David M. Dilts		Title: Director Graduate Studies MOT	
Department/Division: EECS		School/College: Engineering	
Campus Address: Box 1518, Station B		Zip+4:	
Campus Phone: 322-3479	Fax: 322-7996	Pager:	Email: david.dilts@vanderbilt.edu

3. Study Contact Information (complete if primary contact is different from PI) ☐ NA

First Name:	Middle Initial:	Last Name:

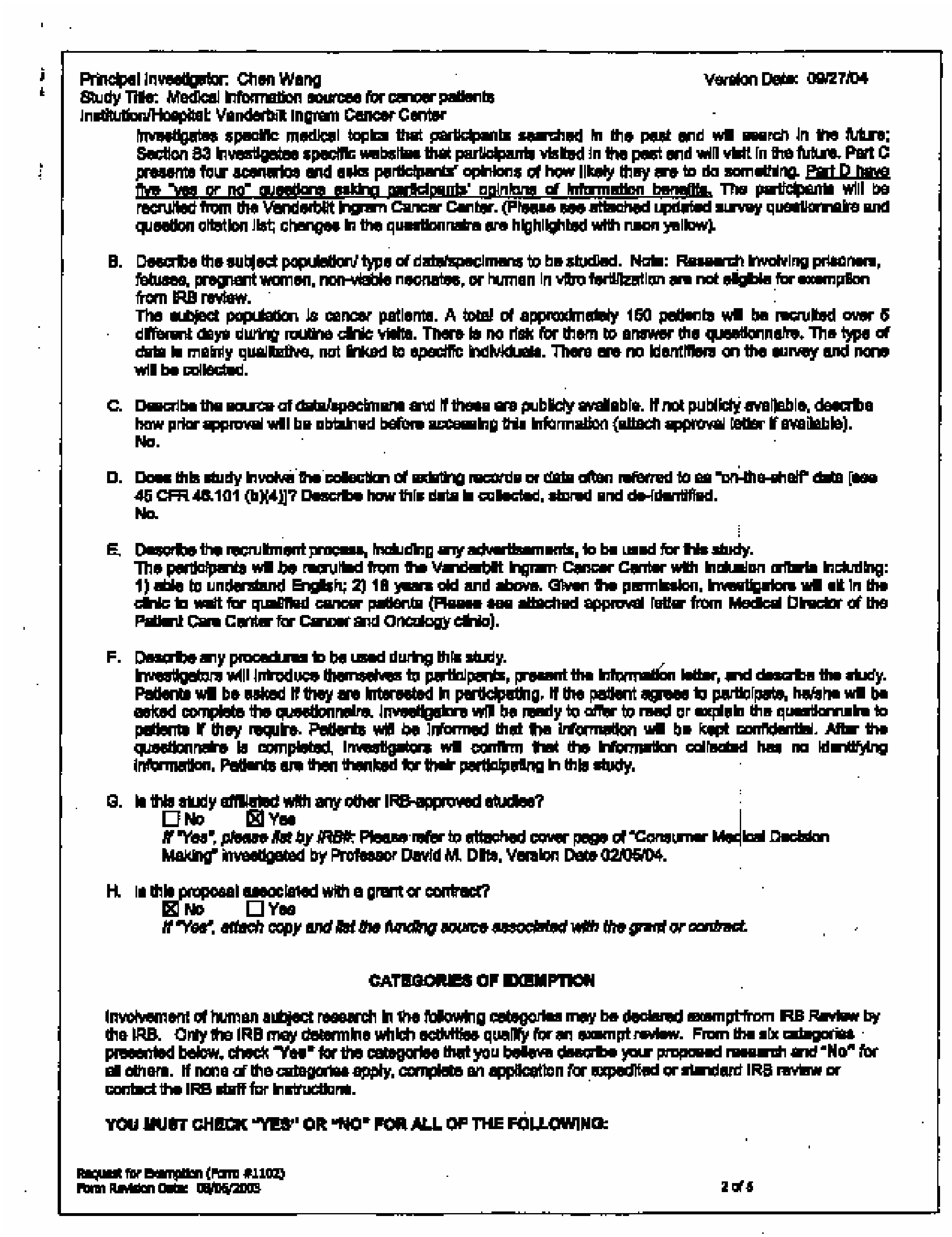
Degree(s): ☐ Ed.D. ☐ J.D. ☐ M.D. ☐ Ph.D. ☐ R.N. ☐ Other, specify:

Job Title:		Affiliation: ☐ VU ☐ Stallworth ☐ VA-TN Valley HS ☐ Other, specify:	
Department/Division:		School/College:	
Campus Address:		Zip+4:	
Campus Phone:	Fax:	Pager:	Email:
Complete if contact does not have campus address:			
Address:		City:	
State:	Zip:	Phone:	

4. Study Information:

A. Give a brief synopsis of the research, including background information and rationale.

Patients use various sources of health information to gain knowledge about their illness and prognosis, treatment options and side effects, ways to prevent recurrence, and psychological resources for coping (Cassileth et al, 1980; Fallowfield et al, 1994). So do their companions (Beach et al, 2004). There is increasing need to present information to consumers that is useful and understandable of medical decision making (Dilts, 2004). The ability to clearly determine patients' and their companions' potential medical information sources can help both physicians and patients to make more efficient communications and decisions together (Dranove, 1988; Labelle et al 1994; Kleffens et al 2003; Beach et al, 2004). Many studies about patient information sources have been done for diseases like heart failure (Gwadry-Sridhar et al, 2003) and AIDS (Reeves 2000). However, despite the extensive literature on information provision for patients with cancer, there are only a limited number of studies that have investigated the preferred sources of information for cancer patients (Mills et al 2002). My survey is to investigate the medical information sources that cancer patients and their companions have visited in the past and prefer to visit in the future, the quality of the medical information they thought or expect from those sources, and their opinions about some related medical situations. <u>There are four parts in this survey: Part A, Part B, Part C, and Part D.</u> Part A investigates demographic information. Part B has three sections: Section B1 investigates participants' medical information sources in the past and potential medical information sources in the future; Section B2



Principal Investigator: Chen Wang Version Date: 09/27/04
Study Title: Medical information sources for cancer patients
Institution/Hospital: Vanderbilt Ingram Cancer Center

investigates specific medical topics that participants searched in the past and will search in the future; Section B3 investigates specific websites that participants visited in the past and will visit in the future. Part C presents four scenarios and asks participants' opinions of how likely they are to do something. <u>Part D have five "yes or no" questions asking participants' opinions of information benefits.</u> The participants will be recruited from the Vanderbilt Ingram Cancer Center. (Please see attached updated survey questionnaire and question citation list; changes in the questionnaire are highlighted with neon yellow).

B. Describe the subject population/ type of data/specimens to be studied. Note: Research involving prisoners, fetuses, pregnant women, non-viable neonates, or human in vitro fertilization are not eligible for exemption from IRB review.
The subject population is cancer patients. A total of approximately 150 patients will be recruited over 5 different days during routine clinic visits. There is no risk for them to answer the questionnaire. The type of data is mainly qualitative, not linked to specific individuals. There are no identifiers on the survey and none will be collected.

C. Describe the source of data/specimens and if these are publicly available. If not publicly available, describe how prior approval will be obtained before accessing this information (attach approval letter if available).
No.

D. Does this study involve the collection of existing records or data often referred to as "on-the-shelf" data [see 45 CFR 46.101 (b)(4)]? Describe how this data is collected, stored and de-identified.
No.

E. Describe the recruitment process, including any advertisements, to be used for this study.
The participants will be recruited from the Vanderbilt Ingram Cancer Center with inclusion criteria including: 1) able to understand English; 2) 18 years old and above. Given the permission, investigators will sit in the clinic to wait for qualified cancer patients (Please see attached approval letter from Medical Director of the Patient Care Center for Cancer and Oncology clinic).

F. Describe any procedures to be used during this study.
Investigators will introduce themselves to participants, present the information letter, and describe the study. Patients will be asked if they are interested in participating. If the patient agrees to participate, he/she will be asked complete the questionnaire. Investigators will be ready to offer to read or explain the questionnaire to patients if they require. Patients will be informed that the information will be kept confidential. After the questionnaire is completed, investigators will confirm that the information collected has no identifying information. Patients are then thanked for their participating in this study.

G. Is this study affiliated with any other IRB-approved studies?
☐ No ☒ Yes
If "Yes", please list by IRB#: Please refer to attached cover page of "Consumer Medical Decision Making" investigated by Professor David M. Dilts, Version Date 02/05/04.

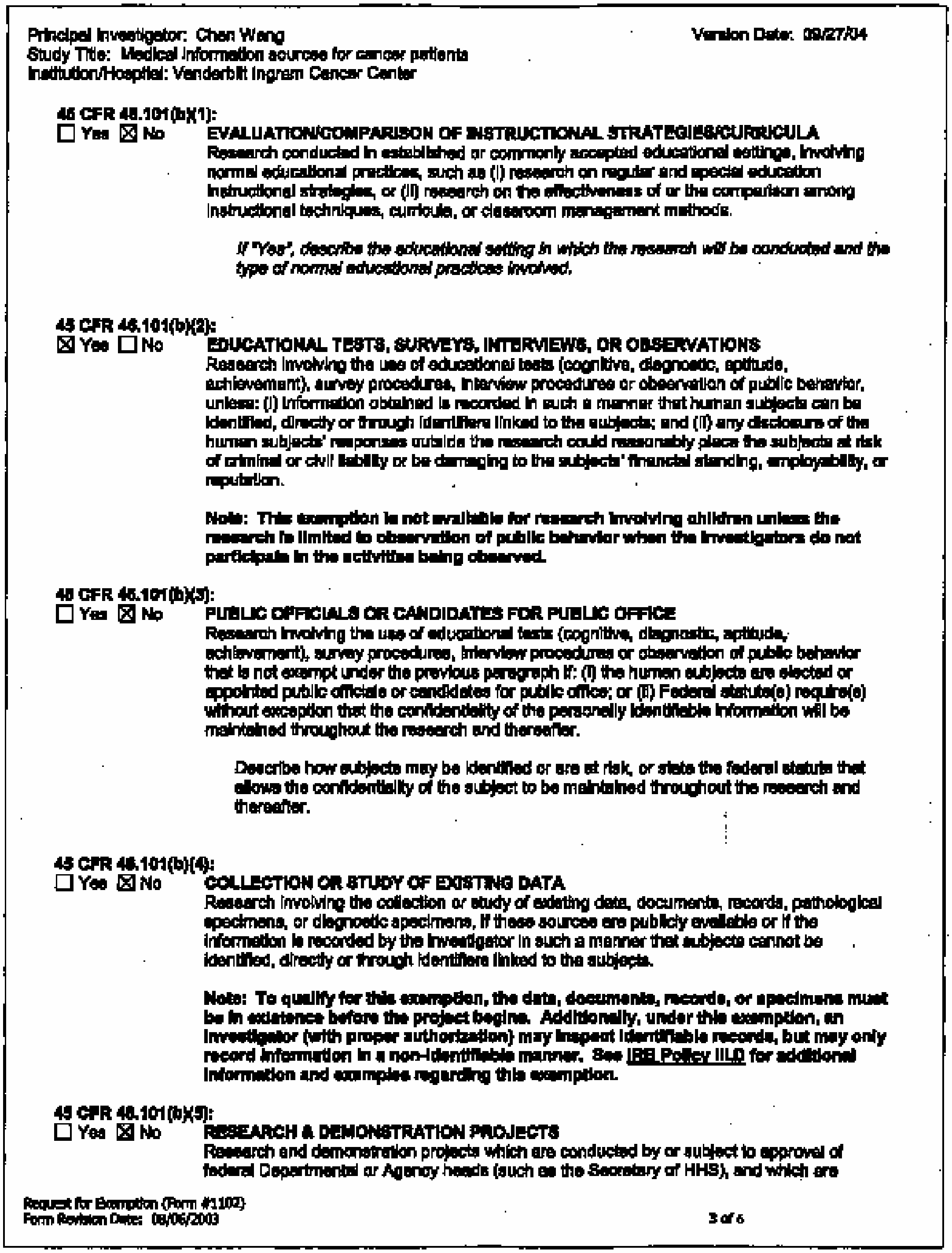
H. Is this proposal associated with a grant or contract?
☒ No ☐ Yes
If "Yes", attach copy and list the funding source associated with the grant or contract.

CATEGORIES OF EXEMPTION

Involvement of human subject research in the following categories may be declared exempt from IRB Review by the IRB. Only the IRB may determine which activities qualify for an exempt review. From the six categories presented below, check "Yes" for the categories that you believe describe your proposed research and "No" for all others. If none of the categories apply, complete an application for expedited or standard IRB review or contact the IRB staff for instructions.

YOU MUST CHECK "YES" OR "NO" FOR ALL OF THE FOLLOWING:

Request for Exemption (Form #1102)
Form Revision Date: 08/06/2003 2 of 5



Principal Investigator: Chen Wang
Study Title: Medical information sources for cancer patients
Institution/Hospital: Vanderbilt Ingram Cancer Center

Version Date: 09/27/04

45 CFR 46.101(b)(1):
☐ Yes ☒ No **EVALUATION/COMPARISON OF INSTRUCTIONAL STRATEGIES/CURRICULA**

Research conducted in established or commonly accepted educational settings, involving normal educational practices, such as (i) research on regular and special education instructional strategies, or (ii) research on the effectiveness of or the comparison among instructional techniques, curricula, or classroom management methods.

If "Yes", describe the educational setting in which the research will be conducted and the type of normal educational practices involved.

45 CFR 46.101(b)(2):
☒ Yes ☐ No **EDUCATIONAL TESTS, SURVEYS, INTERVIEWS, OR OBSERVATIONS**

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.

Note: This exemption is not available for research involving children unless the research is limited to observation of public behavior when the investigators do not participate in the activities being observed.

45 CFR 46.101(b)(3):
☐ Yes ☒ No **PUBLIC OFFICIALS OR CANDIDATES FOR PUBLIC OFFICE**

Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior that is not exempt under the previous paragraph if: (i) the human subjects are elected or appointed public officials or candidates for public office; or (ii) Federal statute(s) require(s) without exception that the confidentiality of the personally identifiable information will be maintained throughout the research and thereafter.

Describe how subjects may be identified or are at risk, or state the federal statute that allows the confidentiality of the subject to be maintained throughout the research and thereafter.

45 CFR 46.101(b)(4):
☐ Yes ☒ No **COLLECTION OR STUDY OF EXISTING DATA**

Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these sources are publicly available or if the information is recorded by the investigator in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects.

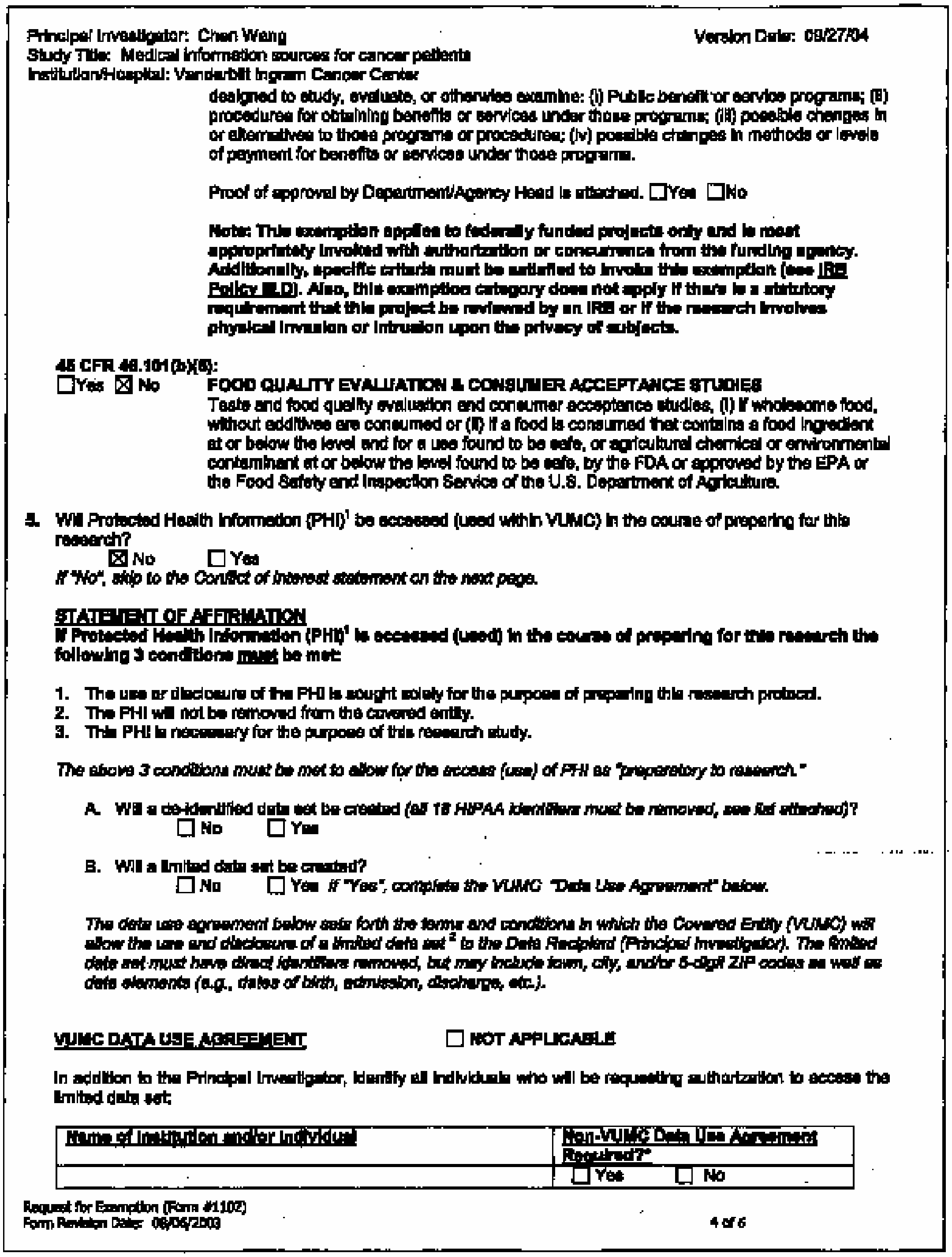
Note: To qualify for this exemption, the data, documents, records, or specimens must be in existence before the project begins. Additionally, under this exemption, an investigator (with proper authorization) may inspect identifiable records, but may only record information in a non-identifiable manner. See IRB Policy III.D for additional information and examples regarding this exemption.

45 CFR 46.101(b)(5):
☐ Yes ☒ No **RESEARCH & DEMONSTRATION PROJECTS**

Research and demonstration projects which are conducted by or subject to approval of federal Departmental or Agency heads (such as the Secretary of HHS), and which are

Request for Exemption (Form #1102)
Form Revision Date: 08/06/2003

3 of 6



Principal Investigator: Chen Wang Version Date: 09/27/04
Study Title: Medical information sources for cancer patients
Institution/Hospital: Vanderbilt Ingram Cancer Center

designed to study, evaluate, or otherwise examine: (i) Public benefit or service programs; (ii) procedures for obtaining benefits or services under those programs; (iii) possible changes in or alternatives to those programs or procedures; (iv) possible changes in methods or levels of payment for benefits or services under those programs.

Proof of approval by Department/Agency Head is attached. ☐Yes ☐No

Note: This exemption applies to federally funded projects only and is most appropriately invoked with authorization or concurrence from the funding agency. Additionally, specific criteria must be satisfied to invoke this exemption (see IRB Policy III.D). Also, this exemption category does not apply if there is a statutory requirement that this project be reviewed by an IRB or if the research involves physical invasion or intrusion upon the privacy of subjects.

45 CFR 46.101(b)(6):
☐Yes ☒ No **FOOD QUALITY EVALUATION & CONSUMER ACCEPTANCE STUDIES**
Taste and food quality evaluation and consumer acceptance studies, (i) if wholesome food, without additives are consumed or (ii) if a food is consumed that contains a food ingredient at or below the level and for a use found to be safe, or agricultural chemical or environmental contaminant at or below the level found to be safe, by the FDA or approved by the EPA or the Food Safety and Inspection Service of the U.S. Department of Agriculture.

5. Will Protected Health Information (PHI)[1] be accessed (used within VUMC) in the course of preparing for this research?
☒ No ☐ Yes
If "No", skip to the Conflict of Interest statement on the next page.

STATEMENT OF AFFIRMATION
If Protected Health Information (PHI)[1] is accessed (used) in the course of preparing for this research the following 3 conditions must be met:

1. The use or disclosure of the PHI is sought solely for the purpose of preparing this research protocol.
2. The PHI will not be removed from the covered entity.
3. This PHI is necessary for the purpose of this research study.

The above 3 conditions must be met to allow for the access (use) of PHI as "preparatory to research."

A. Will a de-identified data set be created *(all 18 HIPAA identifiers must be removed, see list attached)*?
☐ No ☐ Yes

B. Will a limited data set be created?
☐ No ☐ Yes *If "Yes", complete the VUMC "Data Use Agreement" below.*

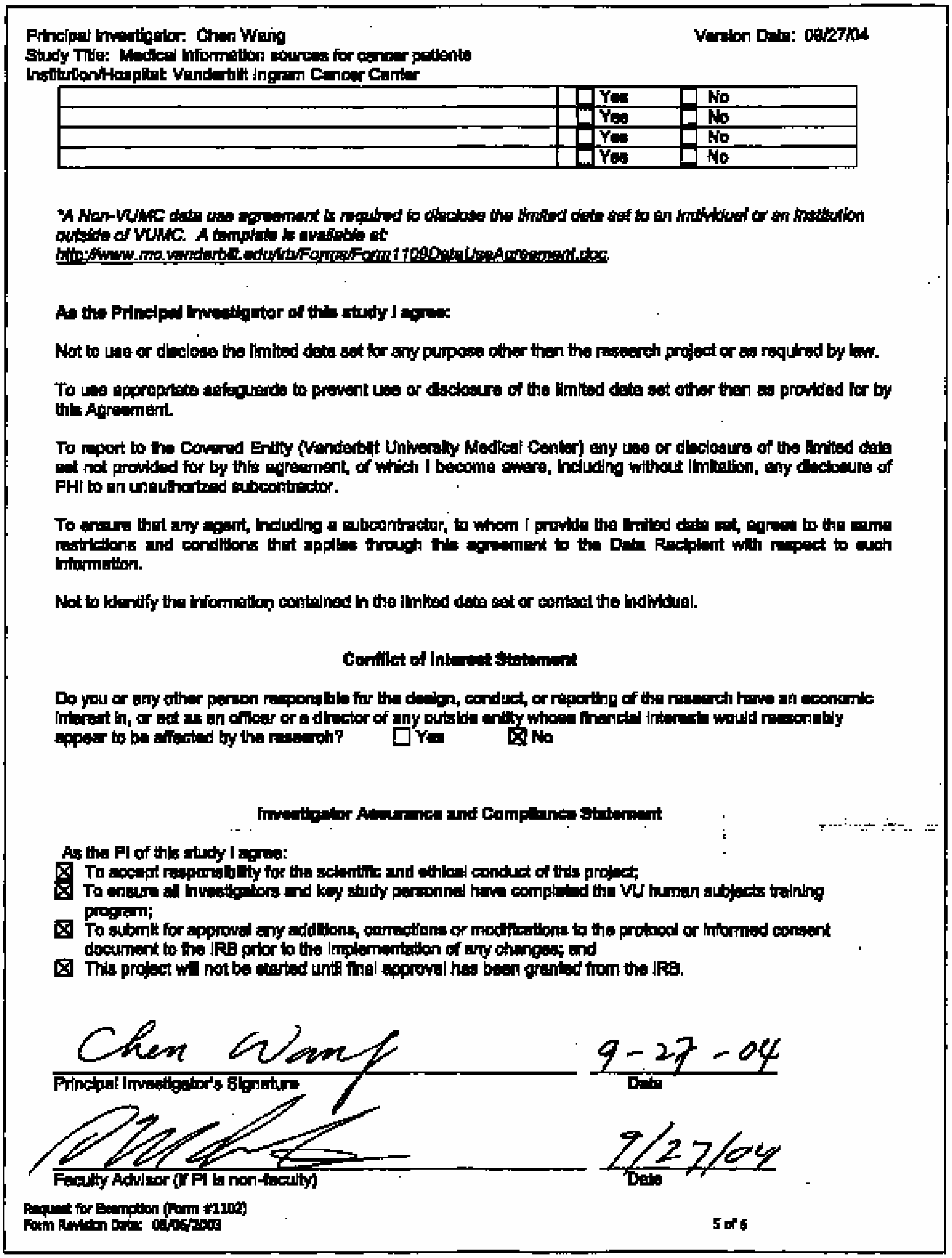
The data use agreement below sets forth the terms and conditions in which the Covered Entity (VUMC) will allow the use and disclosure of a limited data set [2] to the Data Recipient (Principal Investigator). The limited data set must have direct identifiers removed, but may include town, city, and/or 5-digit ZIP codes as well as data elements (e.g., dates of birth, admission, discharge, etc.).

VUMC DATA USE AGREEMENT ☐ **NOT APPLICABLE**

In addition to the Principal Investigator, identify all individuals who will be requesting authorization to access the limited data set:

Name of Institution and/or Individual	Non-VUMC Data Use Agreement Required?*
	☐ Yes ☐ No

Request for Exemption (Form #1102)
Form Revision Date: 08/06/2003 4 of 6



Principal Investigator: Chen Wang **Version Date:** 09/27/04
Study Title: Medical information sources for cancer patients
Institution/Hospital: Vanderbilt Ingram Cancer Center

	☐ Yes	☐ No
	☐ Yes	☐ No
	☐ Yes	☐ No
	☐ Yes	☐ No

******A Non-VUMC data use agreement is required to disclose the limited data set to an individual or an institution outside of VUMC. A template is available at:* *http://www.mc.vanderbilt.edu/irb/Forms/Form1109DataUseAgreement.doc.*

As the Principal Investigator of this study I agree:

Not to use or disclose the limited data set for any purpose other than the research project or as required by law.

To use appropriate safeguards to prevent use or disclosure of the limited data set other than as provided for by this Agreement.

To report to the Covered Entity (Vanderbilt University Medical Center) any use or disclosure of the limited data set not provided for by this agreement, of which I become aware, including without limitation, any disclosure of PHI to an unauthorized subcontractor.

To ensure that any agent, including a subcontractor, to whom I provide the limited data set, agrees to the same restrictions and conditions that applies through this agreement to the Data Recipient with respect to such information.

Not to identify the information contained in the limited data set or contact the individual.

Conflict of Interest Statement

Do you or any other person responsible for the design, conduct, or reporting of the research have an economic interest in, or act as an officer or a director of any outside entity whose financial interests would reasonably appear to be affected by the research? ☐ Yes ☒ No

Investigator Assurance and Compliance Statement

As the PI of this study I agree:
- ☒ To accept responsibility for the scientific and ethical conduct of this project;
- ☒ To ensure all investigators and key study personnel have completed the VU human subjects training program;
- ☒ To submit for approval any additions, corrections or modifications to the protocol or informed consent document to the IRB prior to the implementation of any changes; and
- ☒ This project will not be started until final approval has been granted from the IRB.

Chen Wang 9-27-04
Principal Investigator's Signature Date

9/27/04
Faculty Advisor (if PI is non-faculty) Date

Request for Exemption (Form #1102)
Form Revision Date: 08/06/2003 5 of 6

[1] __Protected Health Information (PHI):__ Protected health information (PHI) is individually identifiable health information that is or has been collected or maintained by Vanderbilt University Medical Center, including information that is collected for research purposes only, and can be linked back to the individual participant. Use or disclosure of such information must follow HIPAA guidelines.

Individually identifiable health information is defined as any information collected from an individual (including demographics) that is created or received by a health care provider, health plan, employer, and/or health care clearinghouse that relates to the past, present or future physical or mental health or condition of an individual, or the provision of health care to an individual or the past, present or future payment for the provision of health care to an individual and identifies the individual and/or to which there is reasonable basis to believe that the information can be used to identify the individual (45 CFR 160.103).

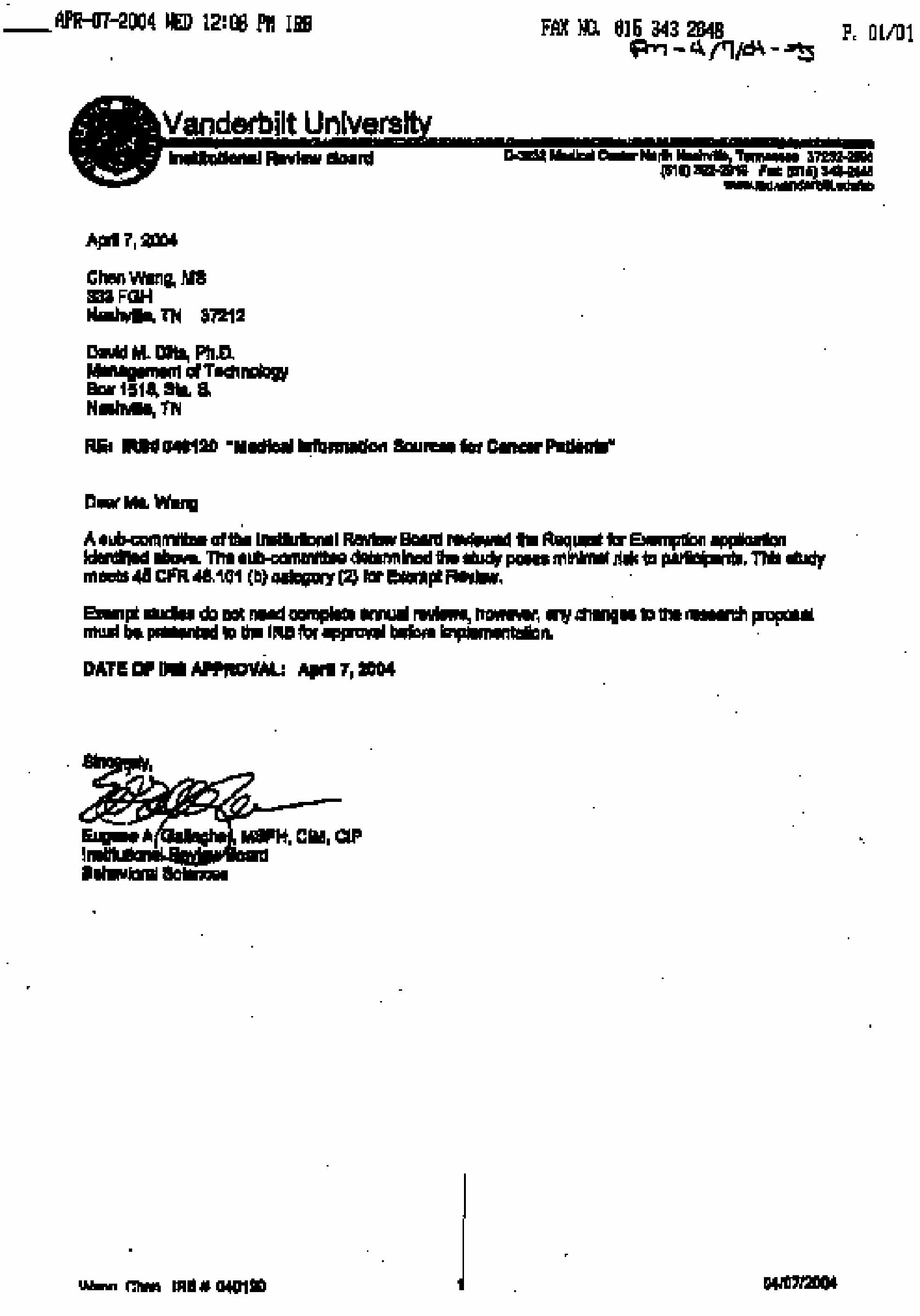
A covered entity (VUMC) may determine that health information is not individually identifiable (De-identified) health information only if all of the following identifiers of the individual or of relatives, employers, or household members of the individual are removed:

1. Names;
2. Any geographic subdivisions smaller than a State, including street address, city, county, precinct, zip code, and their equivalent geocodes, except for the initial three digits of a zip code;
3. All elements of dates (except year) for dates directly related to an individual (e.g., date of birth, admission);
4. Telephone numbers;
5. Fax numbers;
6. Electronic mail addresses;
7. Social security numbers;
8. Medical record numbers;
9. Health plan beneficiary numbers;
10. Account numbers;
11. Certificate/license numbers;
12. Vehicle identifiers and serial numbers, including license plate numbers;
13. Device identifiers and serial numbers;
14. Web Universal Resource Locators (URLs);
15. Internet Protocol (IP) address numbers;
16. Biometric identifiers, including finger and voiceprints;
17. Full-face photographic images and any comparable images; and
18. Any other unique identifying number, characteristic, or code.

[2] __Limited data set:__ The limited data set is protected health information that excludes all above data elements with the exception of elements of dates, geographic information (not as specific as street address), and any other unique identifying element not explicitly excluded in the list above.

APPENDIX M: APPROVAL LETTER FROM IRB

April 07, 2004



APR-07-2004 WED 12:08 PM IRB FAX NO. 615 343 2648 P. 01/01

Rm - 4/7/04 - ts

Vanderbilt University
Institutional Review Board
D-3300 Medical Center North Nashville, Tennessee 37232-[illegible]
(615) 322-2918 Fax (615) 343-2648
www.mc.vanderbilt.edu/irb

April 7, 2004

Chen Wang, MS
333 FGH
Nashville, TN 37212

David M. Dilts, Ph.D.
Management of Technology
Box 1518, Sta. B
Nashville, TN

RE: IRB# 040120 "Medical Information Sources for Cancer Patients"

Dear Ms. Wang

A sub-committee of the Institutional Review Board reviewed the Request for Exemption application identified above. The sub-committee determined the study poses minimal risk to participants. This study meets 45 CFR 46.101 (b) category (2) for Exempt Review.

Exempt studies do not need complete annual reviews, however, any changes to the research proposal must be presented to the IRB for approval before implementation.

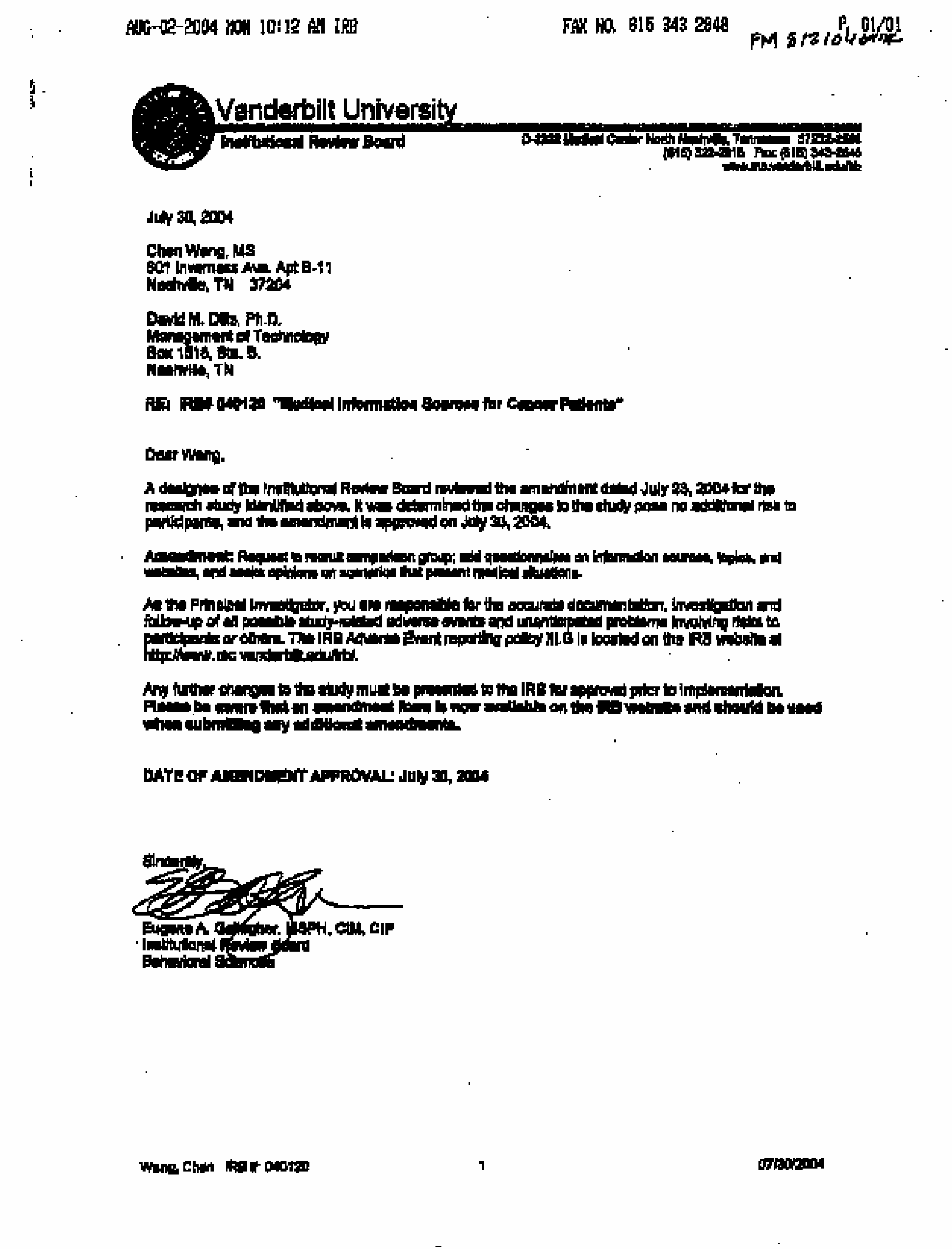
DATE OF IRB APPROVAL: April 7, 2004

Sincerely,

Eugene A. Gallagher, MSPH, CIM, CIP
Institutional Review Board
Behavioral Sciences

Wang, Chen IRB # 040120 1 04/07/2004

July 30, 2004



AUG-02-2004 MON 10:12 AM IRB FAX NO. 615 343 2648 P. 01/01

FM 8/3/04

Vanderbilt University
Institutional Review Board
D-3300 Medical Center North Nashville, Tennessee 37232-2586
(615) 322-2918 Fax (615) 343-2648
www.mc.vanderbilt.edu/irb

July 30, 2004

Chen Wang, MS
801 Inverness Ave. Apt B-11
Nashville, TN 37204

David M. Dilts, Ph.D.
Management of Technology
Box 1518, Sta. B.
Nashville, TN

RE: IRB# 040120 "Medical Information Sources for Cancer Patients"

Dear Wang,

A designee of the Institutional Review Board reviewed the amendment dated July 23, 2004 for the research study identified above. It was determined the changes to the study pose no additional risk to participants, and the amendment is approved on July 30, 2004.

Amendment: Request to recruit comparison group; add questionnaires on information sources, topics, and websites, and seek opinions on scenarios that present medical situations.

As the Principal Investigator, you are responsible for the accurate documentation, investigation and follow-up of all possible study-related adverse events and unanticipated problems involving risks to participants or others. The IRB Adverse Event reporting policy III.G is located on the IRB website at http://www.mc.vanderbilt.edu/irb/.

Any further changes to the study must be presented to the IRB for approval prior to implementation. Please be aware that an amendment form is now available on the IRB website and should be used when submitting any additional amendments.

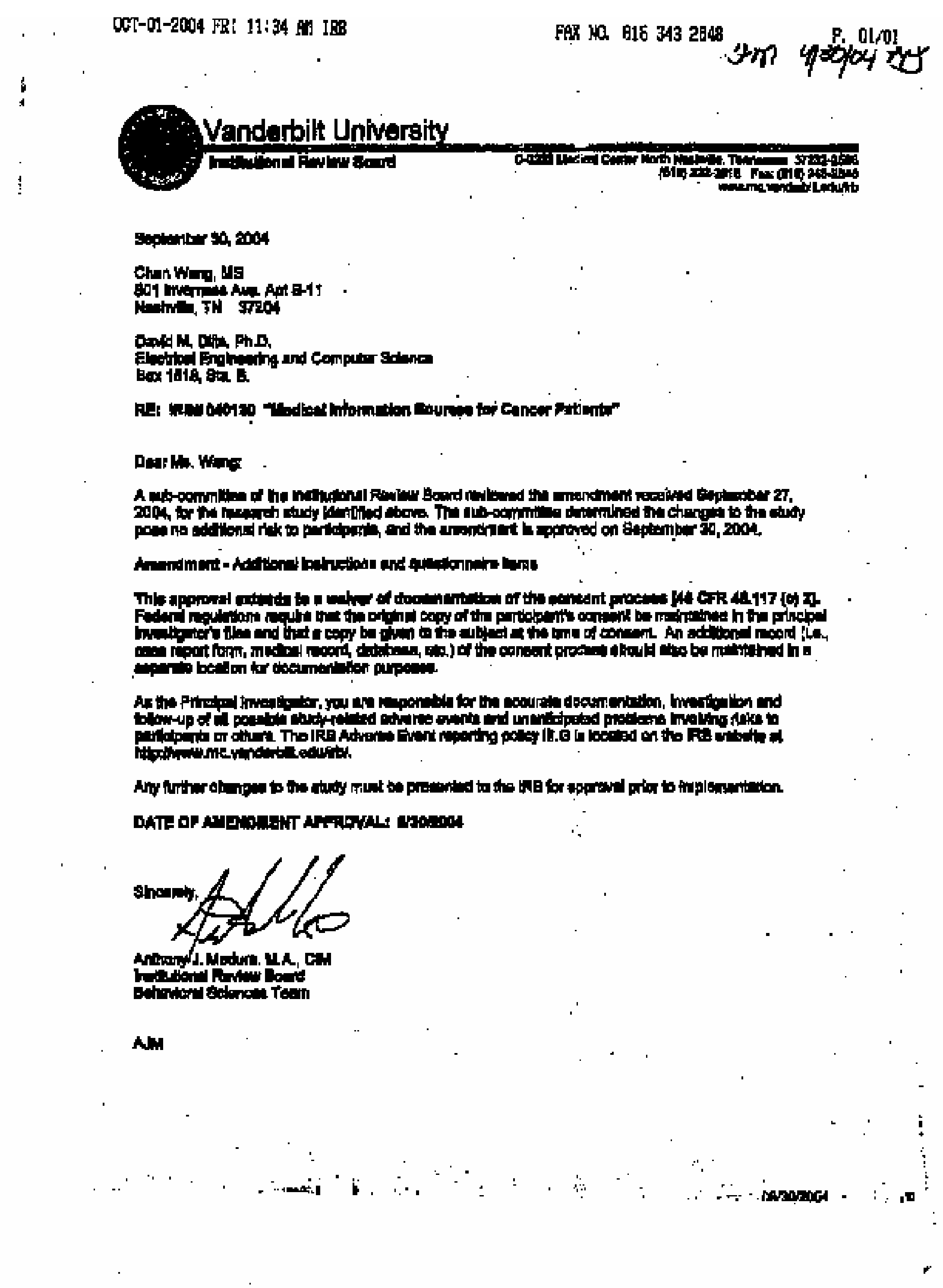
DATE OF AMENDMENT APPROVAL: July 30, 2004

Sincerely,

Eugene A. Gallagher, MSPH, CIM, CIP
Institutional Review Board
Behavioral Sciences

Wang, Chen IRB # 040120 1 07/30/2004

September 30, 2004



OCT-01-2004 FRI 11:34 AM IRB FAX NO. 615 343 2648 P. 01/01

3pm 9/30/04

Vanderbilt University
Institutional Review Board
D-3300 Medical Center North Nashville, Tennessee 37232-[illegible]
(615) 322-2918 Fax (615) 343-2648
www.mc.vanderbilt.edu/irb

September 30, 2004

Chan Wang, MS
801 Inverness Ave. Apt B-11
Nashville, TN 37204

David M. Dilts, Ph.D.
Electrical Engineering and Computer Science
Box 1518, Sta. B.

RE: IRB# 040130 "Medical Information Sources for Cancer Patients"

Dear Ms. Wang:

A sub-committee of the Institutional Review Board reviewed the amendment received September 27, 2004, for the research study identified above. The sub-committee determined the changes to the study pose no additional risk to participants, and the amendment is approved on September 30, 2004.

Amendment - Additional instructions and questionnaire items

This approval extends to a waiver of documentation of the consent process [45 CFR 46.117 (c) 2]. Federal regulations require that the original copy of the participant's consent be maintained in the principal investigator's files and that a copy be given to the subject at the time of consent. An additional record (i.e., case report form, medical record, database, etc.) of the consent process should also be maintained in a separate location for documentation purposes.

As the Principal Investigator, you are responsible for the accurate documentation, investigation and follow-up of all possible study-related adverse events and unanticipated problems involving risks to participants or others. The IRB Adverse Event reporting policy III.G is located on the IRB website at http://www.mc.vanderbilt.edu/irb/.

Any further changes to the study must be presented to the IRB for approval prior to implementation.

DATE OF AMENDMENT APPROVAL: 9/30/2004

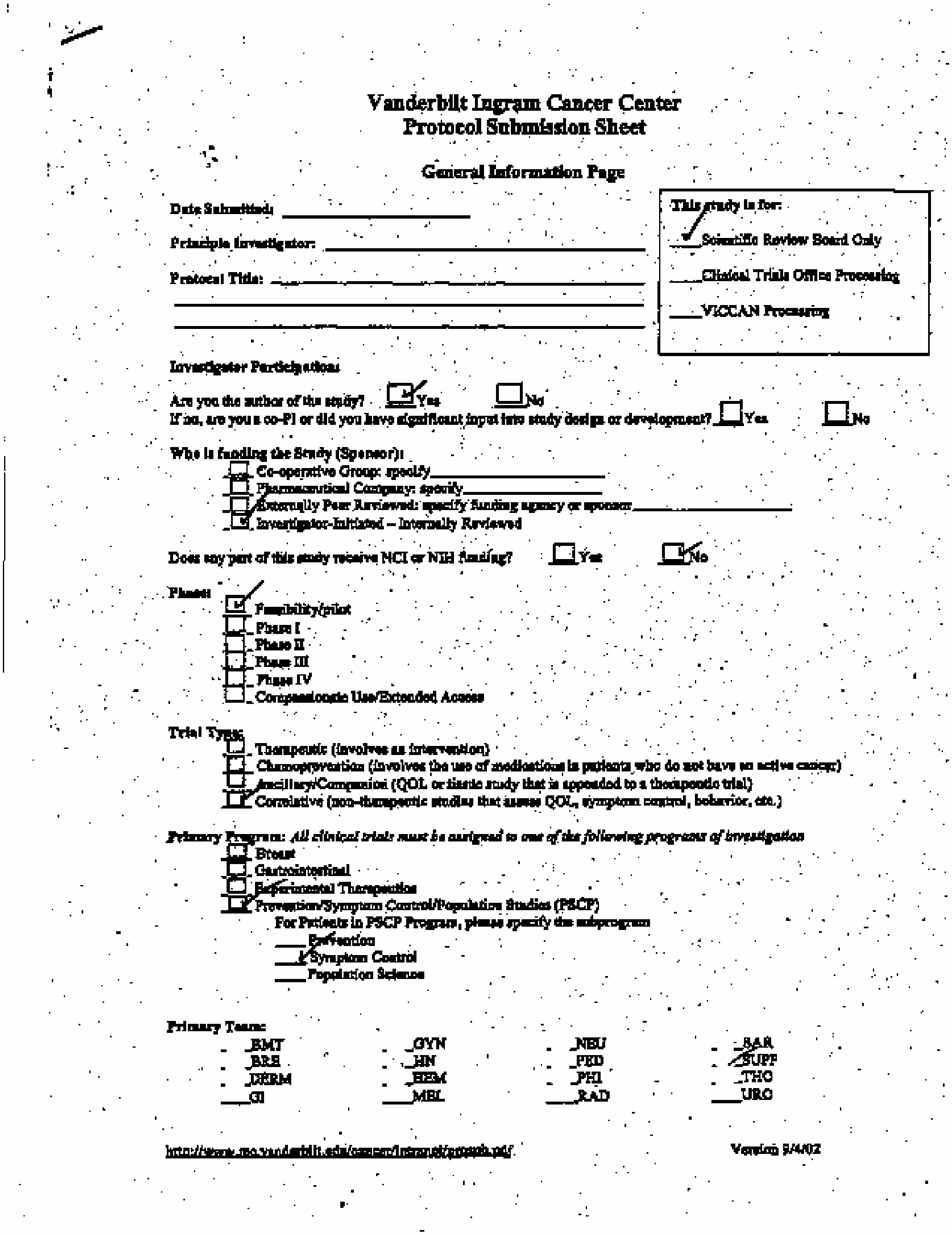
Sincerely,

Anthony J. Madura, M.A., CIM
Institutional Review Board
Behavioral Sciences Team

AJM

09/30/2004

APPENDIX N: PROPOSAL SUMMITTED TO SRC



Vanderbilt Ingram Cancer Center
Protocol Submission Sheet

General Information Page

This study is for:
✓ Scientific Review Board Only
____Clinical Trials Office Processing
____VICCAN Processing

Date Submitted: ____________________

Principle Investigator: ____________________

Protocol Title: ____________________

Investigator Participation:

Are you the author of the study? ☑ Yes ☐ No
If no, are you a co-PI or did you have significant input into study design or development? ☐ Yes ☐ No

Who is funding the Study (Sponsor):
☐ Co-operative Group: specify____________________
☐ Pharmaceutical Company: specify____________________
☐ Externally Peer Reviewed: specify funding agency or sponsor____________________
☑ Investigator-Initiated – Internally Reviewed

Does any part of this study receive NCI or NIH funding? ☐ Yes ☑ No

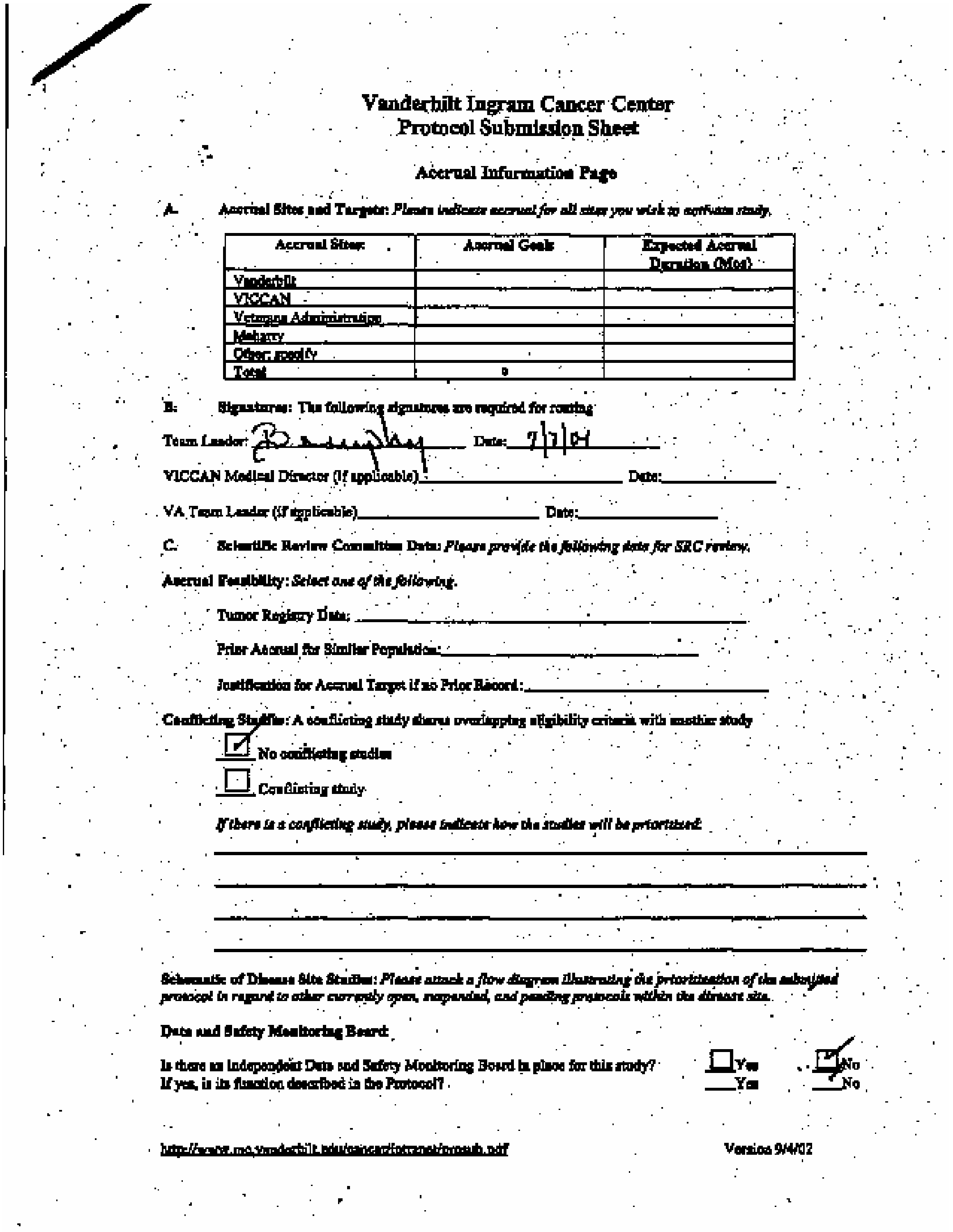
Phase:
☑ Feasibility/pilot
☐ Phase I
☐ Phase II
☐ Phase III
☐ Phase IV
☐ Compassionate Use/Extended Access

Trial Type:
☐ Therapeutic (involves an intervention)
☐ Chemoprevention (involves the use of medications in patients who do not have an active cancer)
☐ Ancillary/Companion (QOL or tissue study that is appended to a therapeutic trial)
☑ Correlative (non-therapeutic studies that assess QOL, symptom control, behavior, etc.)

Primary Program: *All clinical trials must be assigned to one of the following programs of investigation*
☐ Breast
☐ Gastrointestinal
☐ Experimental Therapeutics
☑ Prevention/Symptom Control/Population Studies (PSCP)
For Patients in PSCP Program, please specify the subprogram
____Prevention
__✓_Symptom Control
____Population Science

Primary Team:
_BMT
_BRE
_DERM
____GI
_GYN
_HN
_HEM
____MEL
_NEU
_PED
_PHI
____RAD
_SAR
✓_SUPP
_THO
____URO

http://www.mc.vanderbilt.edu/cancer/internal/protsub.pdf
Version 9/4/02



Vanderbilt Ingram Cancer Center
Protocol Submission Sheet

Accrual Information Page

A. Accrual Sites and Targets: *Please indicate accrual for all sites you wish to activate study.*

Accrual Sites:	Accrual Goals	Expected Accrual Duration (Mos)
Vanderbilt		
VICCAN		
Veterans Administration		
Meharry		
Other, specify		
Total	0	

B: Signatures: The following signatures are required for routing

Team Leader: ____________ Date: 7/7/04

VICCAN Medical Director (If applicable) ____________ Date: ____________

VA Team Leader (If applicable) ____________ Date: ____________

C. Scientific Review Committee Data: *Please provide the following data for SRC review.*

Accrual Feasibility: *Select one of the following.*

Tumor Registry Data: ____________

Prior Accrual for Similar Population: ____________

Justification for Accrual Target if no Prior Record: ____________

Conflicting Studies: A conflicting study shares overlapping eligibility criteria with another study

☑ No conflicting studies

☐ Conflicting study

If there is a conflicting study, please indicate how the studies will be prioritized:

____

____

____

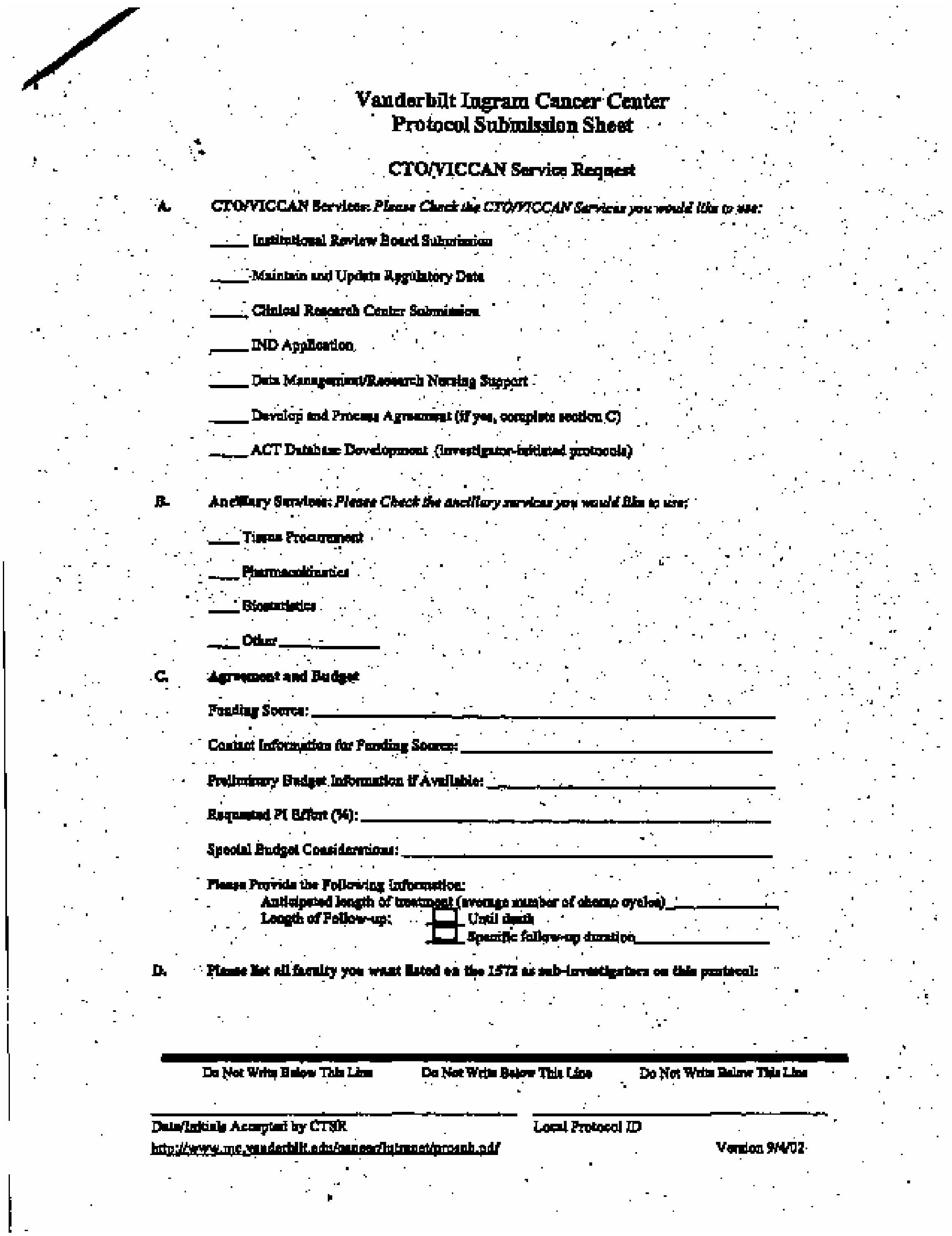
____

Schematic of Disease Site Studies: *Please attach a flow diagram illustrating the prioritization of the submitted protocol in regard to other currently open, suspended, and pending protocols within the disease site.*

Data and Safety Monitoring Board:

Is there an Independent Data and Safety Monitoring Board in place for this study? ☐ Yes ☑ No
If yes, is its function described in the Protocol? ___Yes ___No

http://www.mc.vanderbilt.edu/cancer/intranet/[illegible].pdf Version 9/4/02



Vanderbilt Ingram Cancer Center
Protocol Submission Sheet

CTO/VICCAN Service Request

A. **CTO/VICCAN Services:** ***Please Check the CTO/VICCAN Services you would like to use:***

_____ Institutional Review Board Submission

_____ Maintain and Update Regulatory Data

_____ Clinical Research Center Submission

_____ IND Application

_____ Data Management/Research Nursing Support

_____ Develop and Process Agreement (if yes, complete section C)

_____ ACT Database Development (investigator-initiated protocols)

B. **Ancillary Services:** ***Please Check the ancillary services you would like to use:***

_____ Tissue Procurement

_____ Pharmacokinetics

_____ Biostatistics

_____ Other _____________

C. **Agreement and Budget**

Funding Source: ______________________________

Contact Information for Funding Source: ______________________________

Preliminary Budget Information if Available: ______________________________

Requested PI Effort (%): ______________________________

Special Budget Considerations: ______________________________

Please Provide the Following Information:
Anticipated length of treatment (average number of chemo cycles) _____________
Length of Follow-up: ☐ **Until death**
☐ **Specific follow-up duration** _____________

D. **Please list all faculty you want listed on the 1572 as sub-investigators on this protocol:**

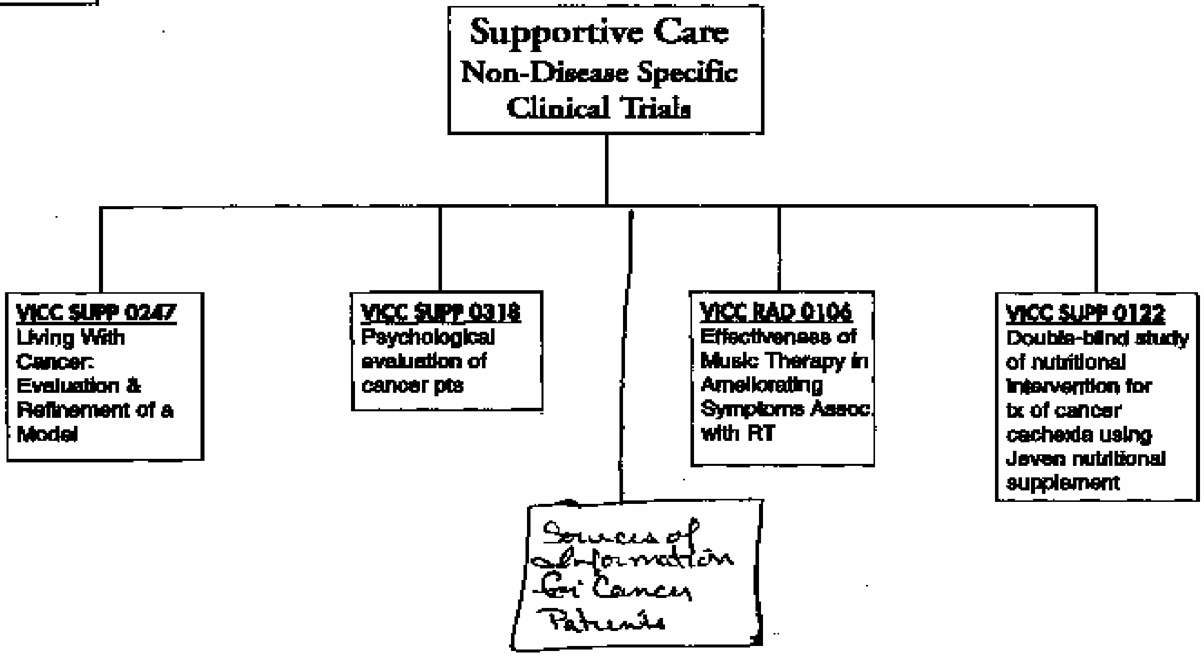
Do Not Write Below This Line **Do Not Write Below This Line** **Do Not Write Below This Line**

______________________________ ______________________________

Date/Initials Accepted by CTSR **Local Protocol ID**

http://www.mc.vanderbilt.edu/cancer/intranet/prosub.pdf **Version 9/4/02**

Click a box below to view trial details.

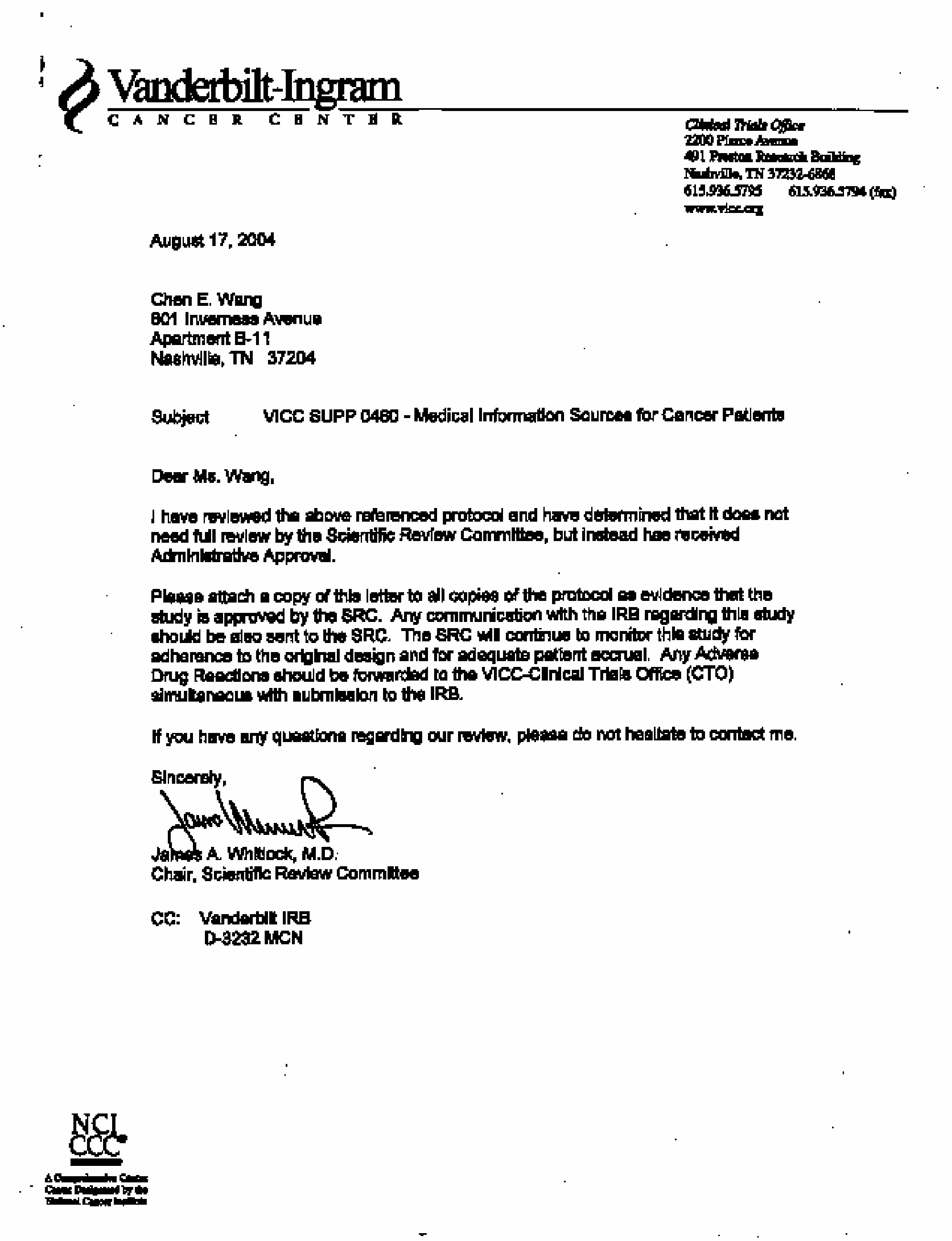


■ Pending
▨ Suspended
☐ Open

Team Leader Signature and Date B. Murphy 4/7/04

Revised 1/14/04

APPENDIX O: APPROVAL LETTER FROM SRC



Vanderbilt-Ingram
CANCER CENTER

Clinical Trials Office
2200 Pierce Avenue
401 Preston Research Building
Nashville, TN 37232-6868
615.936.5795 615.936.5794 (fax)
www.vicc.org

August 17, 2004

Chen E. Wang
601 Inverness Avenue
Apartment B-11
Nashville, TN 37204

Subject VICC SUPP 0460 - Medical Information Sources for Cancer Patients

Dear Ms. Wang,

I have reviewed the above referenced protocol and have determined that it does not need full review by the Scientific Review Committee, but instead has received Administrative Approval.

Please attach a copy of this letter to all copies of the protocol as evidence that the study is approved by the SRC. Any communication with the IRB regarding this study should be also sent to the SRC. The SRC will continue to monitor this study for adherence to the original design and for adequate patient accrual. Any Adverse Drug Reactions should be forwarded to the VICC-Clinical Trials Office (CTO) simultaneous with submission to the IRB.

If you have any questions regarding our review, please do not hesitate to contact me.

Sincerely,

James A. Whitlock, M.D.
Chair, Scientific Review Committee

CC: Vanderbilt IRB
D-3232 MCN

NCI
CCC
A Comprehensive Cancer
Center Designated by the
National Cancer Institute

BIBLIOGRAPHY

Aaker, D. A.; Batra, R.; and Myers, J. G. (1992). *Advertising management*, 4th ed. Englewood Cliffs, NJ: Prentice Hall.

ACS (American Cancer Society). (2004a). Cancer Facts & Figures 2004. Available at: http://www.cancer.org [2004, January 12]

ACS (American Cancer Society). (2004b). What is cancer? Available at http://www.cancer.org [2004, March 08]

Anderson, R.; and Bury, M. (Eds.) (1988). *Living with chronic illness: The experience of patients and their families*. London: Unwin Hyman.

Arraras, Juan Ignacio; Wright, Stephen; Greimel, Eva; Holzner, Bernhard; Kuljanic-Vlasic, Karin; Velikova, Galina; Eisemann, Martin; and Visser, Adriaan. (2003). Development of a questionnaire to evaluate the information needs of cancer patients: the EORTC questionnaire. *Patient Education and Counseling*, In Press, Corrected Proof, Available online 30 October 2003.

Arora, N. K.; Johnson, P.; Gustafson, D. H.; McTavish, F.; Hawkins, R. P.; and Pingree, S. (2002). Barriers to information access, perceived health competence, and psychosocial health outcomes: test of a mediation model in a breast cancer sample. *Patient Educ Couns*, 47, P37-46.

Arrow, K. J. (1979). The economics of information. In M. L. Dertouzos, & J. Moses (Eds.), *The computer age: a twenty year view* (P306-317). Cambridge, MA: MIT Press.

Baker, L. M.; and Pettigrew, K. E. (1999). Theories for practitioners: Two frameworks for studying consumer health information seeking behavior. *Bulletin of Medical Library Association*, 87, P444-450.

Bandura A. (1977). Self-efficacy: towards a unifying theory of behavioral change. *Psychol Rev.*, 84, P191-215.

Bandura A. (1986). *Social foundations of thought and action: a social cognitive theory*. Englewood Cliffs, NJ: Prentice Hall; 1986.

Barber, B. (1983). *The logic and limits of trust*. New Brunswick, NJ: Rutgers University Press.

Barbour G. L.; and Blumenkrantz, M. J. (1978). Videotape aids informed consent decision. *J Am Med Assoc*, 240, P2741-2742.

Basch, Ethan M.; Thaler, Howard T.; Shi, Weiji; Yakren, Sofia; and Schrag, Deborah. (2004). Use of information resources by patients with cancer and their companions. *American Cancer Society*. Available at: www.interscience.wiley.com [2004, May 3]

Bates, B. J. (1988). Information as an economic good: sources of individual and social value. In V. Mosco, & J. Wasco (Eds.), *The political economy of information* (P76-94). Madison, WI: University of Wisconsin Press.

Beaver, K.; Bogg, J.; and Luker, K. A. (1999). Decision-making role preferences and information needs: a comparison of colorectal and breast cancer. *Health Expect*, 2, P266-276.

Belkin, N. J. (1978). Information concepts for information science. *Journal of Documentation*, 34(1), P55-85.

Benjamin-Garner, R; Oakes, JM; Meischke, H; Meshack, A; Stone, EJ; Zapka, J; Finnegan, JR.; Wallace, L; Taylor, J; McGovern, P. (2002). Sociodemographic differences in exposure to health information. *Ethn Dis*., Winter, 12(1), P124-134.

Bero, L.; Jadad, A. R. (1997). How consumers and policymakers can use systematic reviews for decision making. *Ann Intern Med*, 127, P37-42.

Bettman, J. R.; and Park, C. W. (1980). Effects of prior knowledge and experience and phase of the choice process on consumer decision processes. *Journal of Consumer Research*, 7, P234-248.

Bilodeau B. A.; and Degner L. F. (1996). Informational needs, sources of information and decisional roles in women with breast cancer. *Oncol Nurs Forum*, 23(4), P691-696.

Blanchard, C. G.; Labrecque M. S.; Ruckdeschel, J. C.; and Blanchard, E. B. (1988). Information and decision-making preferences of hospitalized adult cancer patients. *Social Science and Medicine*, 27, P1139-1145.

Blanchard, G. C.; Ruckdescel, C. J.; Albrecht, L. T. (1996). Patient-family communication with physicians. *In Cancer and the Family*, P369-387.

Blendon, R.; Brodie, M.; Benson, J. M.; Altman, D. E.; Levitt, L.; Hoff, T.; and Hugick, L. (1998). Understanding the managed care backlash. *Health Affairs*, 17, P80-94.

Blendon, R. ; Hyams, T. S.; and Benson, J. M. (1993). Bridging the gap between expert and public views on health care reform. *Journal of the American Medical Association*, 269, 2573-2578.

Borgers, R.; Mullen, P.D.; Meertens, R.; Rjken, M.; Eussen, G.; Plagge, I.; Visser, A. P.; and Blijham, G. H. (1993). The information seeking behavior of cancer outpatients: a description of the situation. *Patient Education and Counseling*, 22, P35-46.

Boudioni, M.; McPherson, K.; Mossman, J.; Boulton, M.; Jones, A. L.; King, J.; and et al. (1999). An analysis of first-time enquirers to the CancerBACUP information service: variations with cancer site, demographic status and geographical location. *Br J Cancer*, 79, P138-145.

Breemhaar, B.; Visser, A. Ph.; and Kleijnen, J. G. V. M. (1990). Perceptions and behavior among elderly hospital patients: Description and explanation of age differences in satisfaction, knowledge, emotions and behavior. *Social Science & Medicine*, Volume 31, Issue 12, P1377-1385.

Brennan, P. F.; Kuang Y. S.; and Volrathongchai, K. (2000). Patient-centered information systems. Van Bemmel, J. H.; McCray, A. T. (Eds.) *Yearbook of Medical Informatics*. Stuttgart, Germany: Schattauer, P79-86.

Brodie, M.; Flournoy, R. E.; Altman, D. E.; Blendon, R. J.; Benson, J. M.; and Rosenbaum, M. D. (2000). Health information, the Internet, and the digital divide. *Health Aff (Millwood)*, Nov-Dec, 19(6), P255-265.

Brown, P.; Ames, N.; Metteger, W.; Smith, T. J.; Gramarossa, G. L.; Friedell, G. H.; and McDonald, S. S. (1993). Closing the comprehension gap: Low literacy and the cancer information service. *Journal of National Cancer Institute Monograph*, 14, P157-163.

Buckland, M. K. (1991). Information as thing. *Journal for Information Science*, 42(5), P351-360.

Burnkrant, R. E. (1976). A motivational model of information-processing intensity. *Journal of Consumer Research*, 3, P21-30.

Burrows, M; Dibble, SL; Miaskowski, C. (1998). Differences in outcomes among patients experiencing different types of cancer-related pain. *Oncology Nursing Forum*, May, 25(4), P735-741.

Bury, M. (1991). The sociology of chronic illness: A review of research and prospects. *Sociology of Health & Illness*, 13(4), P451-468.

Bury, M. (1997). *Health & illness in a changing society*. London: Routledge.

Buseh, Aaron G.; Glass, Laurie K.; McElmurry, Beverly J.; Mkhabela, Mildred; and Sukati, Nonhlanhla A. (2002). Primary and preferred sources for HIV/AIDS and sexual risk behavior information among adolescents in Swaziland, Southern Africa. *International Journal of Nursing Studies*, Volume 39, Issue 5, July, P525-538.

Butow, P.; Brindle, E.; McConnell, D.; and et al. (1998). Information booklets about cancer: factors influencing patient satisfaction and utilization. *Patient Edu Couns*, 33, P129-141.

Butow, P.; Dunn S.; Tattersall M.; and Jones Q. (1994). Computer-based interaction analysis of the cancer consultation. *Br J Cancer*, 71, P1115-1121.

Butow, P. N.; Tattersall, M.H.; and Goldstein, D. (1997). Cancer patients' preferences for information, involvement and support. *Ann Oncol*, 8, P857-863.

Byrne, P.; Long, B. *Doctors talking to patients*. London: Department of Health and Social Security, 1976.

Cameron, P.; Corbett, K.; Duncan, C.; Hegyi, K.; Maxwell, H.; and Burton, P. F. (1994). Information needs of hospital patients: a survey of satisfaction levels in a large city hospital. *Journal of Documentation*, 50, P10-23.

Carlsson, Maria. (2000). Cancer patients seeking information from sources outside the health care system. *Support Care Cancer*, Volume 8, 453-457.

Carlsson, M; Strang P. (1998). A controlled study of an educational support program for patients with gynecological cancer and their families. *Acta Oncology*, 37, P269-275.

Carlsson, M; Strang P. (1999). Educational group support for patients with gynecological cancer and their families. *Support Care Cancer*, 4, P102-109.

Cassileth, B. R.; Zupkis, R. V.; Sutton-Smith, K. V.; March V. (1980). Informational and participation preferences among cancer patients. *Ann Intern Med*, 92, P832-837.

Cawley, M.; Kostic, J; and Cappello, C. (1990). Informational and psychosocial needs of women choosing conservative surgery/primary radiation for early stage breast cancer. *Cancer Nurs*, 13, P90-94.

Champman, K; Rush, K. (2003). Patient and family satisfaction with cancer-related information: a review of the literature. *Can Oncol Nurs J.*, 13, P107-116.

Chen, X; Siu, LL. (2001). Impact of the media and the Internet on oncology: survey of cancer patients and oncologists in Canada. *J Clin Oncol*, 19, P4291-4297.

Chew, F. (1994). The relationship of information needs to issue relevance and media use. *Journalism Quarterly*, 71, P676-688.

Childers, T. (1975). *The information-poor in America*. Metuchen, NJ: Scarecrow.

Clemen, Robert T.; and Reilly, Terence. (2001). *Making Hard Decisions (2nd Edition)*. Pacific Grove, CA: Duxbury; 2001.

Cohn, Wendy F.; Ropka, Mary E.; Jones, Susan M.; Miesfeldt, Susan. (2003). Information needs about hereditary breast cancer among women with early-onset breast cancer. *Cancer Detection and Prevention*, Volume 27, Issue 5, 345-352.

Connell, C. M.; and Crawford, C. O. (1988). How people obtain their health information: a survey in two Pennsylvania counties. *Public Health Reports*, 103, P189-195.

Conesa, C.; Zambudio, A. Rios; Ramirez, P.; Canteras, M.; Rodriguez, M. M.; and Parrilla, P. (2004). Influence of different sources of information on attitude toward organ donation: a factor analysis. *Transplantation Proceedings*, 36, P1245-1248.

Cooley, M. E.; Moriarty, H.; Berger, M. S.; and et al. (1995). Patient literacy and the readability of written cancer educational materials. *Oncol Nurs Forum*, 22, P1345-51.

Coulter A. (1999). Paternalism or partnership? Editorial. *BMJ*, 319 (7212), P719.

Coulter A. (2003). Patient information and shared decision-making in cancer care. *Br J Cancer*, 89 Suppl. 1, S15-S16.

Coulter, A.; and Cleary, P. D. (2001). Patients' experiences with hospital care in five countries. *Health Affairs*, 20, P244-252.

Czaja, R; Manfredi, C; Price, J. (2003). The determinants and consequences of information seeking among cancer patients. *Journal of Health Communication*, Nov-Dec, 8 (6): P529-562.

Damian, D.; and Tattersall, M. H. (1991). Letters to patients: improving communication in cancer care. *Lancet*, 338, P923-992.

Department of Health. (1995). *A policy framework for commissioning cancer services* (Calman-Hine Report). London: The Stationery Office.

Department of Health. (2000). *The NHS Cancer Plan: A plan for investment. A plan for reform.* London: HMSO.

Derdiarian A. (1987). Informational needs of recently diagnosed cancer patients. Method and Description. Part 2. *Cancer Nurs*, 10(3), P156-163.

Dervin, B. (1997). Given a context by any other name: Methodological tools for taming the unruly beast. In P. Vakkari, R. Savolainen, & B. Dervin (Eds.), *Information seeking in context* (P13-38). London: Taylor Graham.

Dervin, B.; Harlock, S.; Atwood, R.; and Garzona, C. (1980). The human side of information: An exploration in a health communication context. In D. Nimmo (Ed.), *Communication yearbook 4* (P591-608). New Brunswick, NJ: Transaction Books.

Dervin, B.; Nilan, M. S.; and Jacobson, T. L. (1982). Improving predictions of information use: A comparison of predictor types in a health communication setting. In M. Burgoon (Ed.), *Communication yearbook 5* (P419-445). Beverly Hills, CA: Sage.

Dervin, B. (1983). An overview of sense-making research: concepts, methods and results to date. Paper presented at the International Communications Association Annual Meeting, Dallas, May.

Dervin, B.; and Nilan, M. S. (1986). Information needs and uses. *Annual Review of Information Science and Technology*, 21, P3-33.

Devine, E. C.; and Westlake, S. K. (1995). The effects of psychoeducational care provided to adults with cancer: meta-analysis of 116 studies. *Oncol Nurs Forum*, 22, P1369-1381.

Diaz, Joseph A.; Griffith, Rebecca A., NG, James J.; Reinert, Steven E.; Friedmann, Peter D.; Moulton, Anne W. (2002). Patients' use of the Internet for medical information. *J Gen Intern Med*, 17, 180-185.

Diefenbach, M. A.; Dorsey, J.; Uzzo, R. G.; Hanks, G. E.; Greenberg, R. E.; Horwitz, E.; and et al. (2002). Decision-making strategies for patients with localized prostate cancer. *Semin Urol Oncol*, 20, P55-62.

Dilts, D. M.; B. Murphy; A. Franco. (2003). Will Cancer Patients Use E-mail. *Journal of Clinical Oncology.*

Doak, C. C.; Doak, L. G.; and Root, J. H. (1996). *Teaching patients with low literacy skills*. 2nd ed. Philadelphia: J. B. Lippincott.

Dranove, D. (1988). Demand inducement and the physician/patient relationship. *Econ Inq.*, 26(2), Apr., P281-298.

Ellis, D. (1989). A behavioral approach to information retrieval system design. *Journal of Documentation*, 45, P171-212.

Eng, T. R.; Maxfield, A.; Patrick, K.; Deering, M. J.; Ratzan, S. C.; and Gustafson, D. H. (1998). Access to health information and support: a public highway or private road? *JAMA*, Oct, 280(15), P1371-1375.

Eriksson, E.; and Lauri, S. (2000). Informational and emotional support for cancer patients relatives. *European Journal of Cancer Care*, 9, P8-15.

Errington, A. (1986). The delegation of decisions on the farm. *Agricultural Systems*, 19, P299-317.

Eysenbach, G. (2000). Consumer health informatics. *BMJ*, 320, P1713-1716.

Eysenbach, G. (2003). The impact of the Internet on cancer outcomes. *CA Cancer J Clin*, 53, P356-371.

Eysenbach, G.; and Diepgen, T, L. (2000). Patients looking for information on the Internet and seeking teleadvice: motivation, expectations, and misconceptions as expressed in emails sent to physicians. *Arch Derm*, 135, P151-156.

Fallowfield, L. J.; Ford, S.; and Lewis, S. (1994). Information preferences of patients with cancer. *Lancet*, 344(8936), P1576.

Fallowfield, L. J.; Hall, A.; Maguire, G. P.; and Baum, M. (1990). Psychological outcomes of different treatment policies in women with early breast cancer outside a clinical trial. *BMJ*, 301, P575-580.

Fallowfield, L. J.; Lord, S.; and Lewis, S. (1995). Now news is not good news: information preferences of patients with cancer. *Psychooncology*, 4, P197-202.

FACTA (Fair and Accurate Credit Transactions Act) of 2003, Medical Information Rulemaking. 603(i).

Fiske, J. (1990). *Introduction to communication studies*, 2nd ed. London: Routledge.

Fogel, J.; Albert, S. M.; Schnabel, F.; Ditkoff, B. A.; and Neugut, A. I. (2002). Use of the Internet by women with breast cancer. *J Med Internet Res*, Apr-Nov, 4(2),e9.

Folkman, S. (1984). Personal control and stress and coping processes: a theoretical analysis. *Journal of Personality and Social Psychology*, 46, P839-852.

Fontanarosa, P. B.; Flanagin, A.; and DeAngelisk C. D. (2000). The journal's policy regarding release of information to the public. *JAMA*, 284, P2929-2931.

Ford, S.; Fallowfield, L.; and Lewis S. (1995). Doctor-patient interactions in oncology. *Social Science and Medicine*, 00, P1-9.

Ford, S. A.; and Babb, E. Y. (1989). Farmers sources and use of information. *Agribusiness*, 5, P465-476.

Forsythe, D. E. Buchanan, B. G.; Osheroff, J. A.; and Miller, R. A. (1992). Expanding the concept of medical information: an observational study of physicians' information needs. *Compu Biom Res*, 25, P181-200.

Fox, C. J. (1983). *Information and misinformation: an investigation of the notions of information and misinformation, informing and misinforming*. Westport, CT: Greenwood.

Fox, Susannah; and Fallows, Deborah. (2003). Internet Health Resources. *Pew Internet & American Life Project*. Available at: http://www.pewinternet.org/reports [2003, July 16]

Fox, S.; and Rainee, L. (2000). The online health care revolution: how the Web helps Americans take better care of themselves. Washington, DC: *Pew Internet & American Life Project*. Available at: http://www.pewinternet.org/reports [2003, July 16]

Frank, A. W. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago & London: University of Chicago Press.

Franks, Peter; Campbell, Thomas L.; and Shields, Cleveland G. (1992). Social relationships and health: The relative roles of family functioning and social support, *Social Science & Medicine*, Volume 34, Issue 7, April, P779-788.

Freimuth, V. S. (1993). Narrowing the cancer knowledge gap between whites and African Americans. *Journal of National Cancer Institute Monograph*, 14, P81-91.

Gagliano, M. E. (1988). A literature review on the efficacy of video in patient education. *J Med Edu*, 63, P785-792.

Germino, B. B.; Mishel, M. H.; Belyea, M.; Harris, L.; Ware, A.; Mohler, J. (1998). Uncertainty in prostate cancer. Ethnic and family patterns. *Cancer Pract*, 6, P107-113.

Goffman, E. (1974). *Frame analysis: An essay on the organization of experience*. Cambridge, MA: Harvard University Press.

Gollop, C. J. (1997). Health information-seeking behavior and older African-American women. *BMLA*, 85, P141-146.

Gotay, C. C. (1996). Cultural Variation in family adjustment to cancer. *In Cancer and the Family*, P32-52.

Gottlieb, N. (2001). The age of breast cancer awareness: what is the effect of media coverage? *J. Natl. Cancer Inst.*, 93, P1520-1522.

Grol, R.; Wensing, M.; Mainz, J.; Jung, H. P.; Ferreira, P.; Hearnshaw, H.; Hjortdahl, P.; Olesen, F.; Reis, S.; Ribacke, M.; Szecsenyi, J. (2000). Patients in Europe evaluate general practice care: an international comparison. *European Task Force on Patient Evaluations of General Practice Care*, 50, P882-887.

Grossarth-Maticek, R.; Eysenck, H. J.; Pfeifer, A.; Schmidt, P.; and Koppel, G. (1997). The specific action of different personality risk factors on cancer of the breast, cervix, corpus uteri and other types of cancer: A prospective investigation. *Personality and Individual Differences*, Volume 23, Issue 6, December, P949-960.

Guidry, JJ; Aday, LA; Zhang, D; Winn, RJ. (1998). Information sources and barriers to cancer treatment by racial/ethnic minority status of patients. *Journal of Cancer Education*, Spring, 13(1), P43-48.

Gwadry-Sridhar, Femida; Guyatt, Gordon H.; Arnold, Malcolm O.; Massel, David; Brown, Jim; Nadeau, Lorraine; Lawrence, Sharon. (2003). Instruments to measure acceptability of information and acquisition of knowledge in patients with heart failure. *The European Journal of Heart Failure,* In Press, Corrected Proof, Available online 8 October 2003.

Hack, T; Degener, L; and Dyck, D. (1994). Relationship between preferences for decisional control and illness information among women with breast cancer: a quantitative and qualitative analysis. *Social Science & Medicine*, 39, P279-289.

Hardwick, C. and Lawson, N. (1995). The information and learning needs of the caregiving family of the adult patient with cancer. *Eur J Cancer Care (Engl)*, 4, P118-121.

Harris, K. A. (1998). The informational needs of patients with cancer and their families. *Cancer Practice*, 6(1), P39-46.

Harrison, R.; Dey, P.; Slevin, N. J.; and et al. (2001). Randomized controlled trial to assess the effectiveness of a videotape about radiotherapy. *Br J Cancer*, 84, P8-10.

Harrison-Woermke, D. E.; and Graydon, J E. (1993). Perceived informational needs of breast cancer patients receiving radiation therapy after excisional biopsy and axillary node dissection. *Cancer Nurs*, 16, P449-455.

Hayes, R. M. (1993). Measurement of information and communication: a set of definitions. In J. R. Schement, & B. D. Ruben (Eds.), *Information and behavior* (Vol. 4, P2-33). New Brunswick, NJ: Transaction.

Heaton, J. (1999). The gaze and visibility of the carer: A Foundation analysis of the discourse of informal care. *Sociology of Health & Illness*, 21 (6), P759-777.

Hertzum, Morten; Andersen, Hans H. K.; Verner Andersen; and Hansen, Camilla B. (2002). Trust in information sources: seeking information from people, documents, and virtual agents. *Interacting with Computers*, Volume 14, Issue 5, October, P575-599.

Hinds, C; Streater, A.; and Mood, D. (1995). Functions and preferred methods of receiving information related to radiotherapy. Perceptions of patients with cancer. *Cancer Nursing*, 18, P374-384.

Hoffman-Goetz, L.; and Clarke, J. N. (2000). Quality of breast cancer sites on the World Wide Web. *Can J Public Health*, 91, P281-284.

Hogben, B.; and Fallowfield, L. (1989). Getting it taped: the “bad news” consultation with cancer patients. *Br J Hops Med*, 41, P330-333.

Horrigan, John; Lenhart, Amanda; Spooner, Tom; Burke, Maura; Lewis, Oliver; Carter, Cornelia. (2000). The online health care revolution: how the web helps Americans take better care of themselves. *Pew Internet & American Life Project*. Available at: http://www.pewinternet.org/reports [2000, November 26]

Horrigan, John; Rainie, Lee. (2000). Counting on the Internet. *Pew Internet & American Life Project*. Available at: http://www.pewinternet.org/reports [2002, December 29]

Houts, P.; Rusenas, I.; Simmonds, M.; and Hufford, D. (1991). Information needs of families of cancer patients: a literature review and recommendations. *J Cancer Edu*, 6, P225-261.

Humphrey, G. B.; Littlewood, J. L.; Kamps, W. A. (1992). Physician/patient communication: a model considering the interaction of physicians' therapeutic strategy and patients' coping style. *J Cancer Educ*, 7, P147-152.

Jadad, A. R.; Cook, D. J.; Jones, A.; Klassen, T. P.; Tugwell, P.; Moher, M.; and Moher, D. (1998). Methodology and reports of systematic reviews and meta-analyses: a comparison of Cochrane reviews with articles published in paper-based journals. *JAMA*, 208, P278-280.

James, Carolyn; James, Nicholas; Davies, David; Harvey, Peter; Tweddle, Sally. (1999). Preferences for different sources of information about cancer. *Patient Education and Counseling*, Volume 37, Issue 3, July, 273-282.

Jenkins, V.; Fallowfield, L.; and Saul, J. (2001). Information needs of patients with cancer: results from a large study in UK cancer centers. *Br J Cancer*, 84(1), P48-51.

Johnson, I. A.; and Adelstein, D. J. (1991). The use of recorded interviews to enhance physician-patient communication. *J Cancer Educ*, 6, P99-102.

Johnson, J. David. (1993a). *Organized Communication Structure*. Norwood, NJ: Ablex Publishing Co.

Johnson, J. David. (1993b). *Tests of a comprehensive model of cancer-related information seeking*. Paper read at the Speech Communication Association Annual Convention, Miami, FL.

Johnson, J. David. (1996). *Information seeking: An organizational dilemma*. Westport, CT: Quorom Books.

Johnson, J. David. (1997). *Cancer-related information seeking*. Cresskill, NJ: Hampton Press.

Johnson, J. David. (2003). On contexts of information seeking. *Information Processing & Management*, Volume 39, Issue 5, September, P735-760.

Johnson, J. David; Andrews; James E.; and Allard, Suzie. (2001). A model for understanding and affecting cancer genetics information seeking. *Library & Information Science Research*, Volume 23, Issue 4, Winter, P335-349.

Johnson J. David; and Meischke H. (1991a). Cancer information: women's source and content preferences. *J Health Care Marketing*, Volume 11, P37-44.

Johnson J. David; Meischke H. (1991b). Women's preferences for cancer information from specific communication channels. *American Behavioral Scientist*, 34 (6), P742-755.

Johnson J. David; and Meischke H. (1993). A comprehensive model of cancer-related information seeking applied to magazines. *Human Communication Research*, Volume 19, P343-367.

Johnson, J. E.; Nail, L. M.; Lauver, D.; King, K. B.; Keys, H. (1988). Reducing the negative impact of radiation therapy on functional status. *Cancer*, 61, P46-51.

Johnson, L. C.; and Macrae, C. N. (1994). Changing social stereotypes: the case of the information seeker. *European Journal of Social Psychology*, 24, P581-592.

Juarez, G.; Ferrell, B.; and Borneman, T. (1999). Cultural considerations in education for cancer pain management. *J Cancer Educ*, 14, P168-173.

Jubelirer, S. J.; Linton, J. C.; and Magnetti, S. M. (1994). Reading versus comprehension: Implications for patient education and consent in an outpatient oncology clinic. *Journal of Cancer Education*, 9(1), P26-29.

Jung, Hans Peter; Baerveldt, Cor; Olesen, Frede; Grol, Richard; and Wensing, Michel. (2003). Patient characteristics as predictors of primary health care preferences: a systematic literature analysis. *Health Expectations*, 6, P160-181.

Junghans, Theodore B.; Sevin, Imogene F.; Ionin, Boris; and Seifried, Harold. (2004). Cancer information resources: digital and online sources. *Toxicology*, Volume 198, Issues 1-3, 20 May, P177-193.

Kakai, Hisako; Maskarinec, Gertraud; Shumay, Dianne M.; Tatsumura, Yvonne; Tasaki, Katsuya. (2003). Ethnic differences in choices of health information by cancer patients using complementary and alternative medicine: an exploratory study with correspondence analysis. *Social Science & Medicine*, Volume 56, Issue 4, February, 851-862.

Kaplan, S. H.; Greenfield, S.; Gandek, B.; and et al. (1996). Characteristics of physicians with participatory decision-making styles. *Ann Intern Med*, 124, P497-504.

Kassirer, J. P. (2000). Patients, physicians, and the Internet. *Health Aff (Millwood)*, 19, P115-123.

Kassulke, D.; Stenner, D. K.; Coory, M.; and Ring, I. (1993). Information seeking behavior and sources of health information: associations with risk factors status in an analysis of three Queensland electorates. *Australian Journal of Public Health*, 17, P51-57.

Kelly, M.; and Field, D. (1996). Medical sociology, chronic illness and the body. *Sociology of Health & Illness*, 18 (2), P241-257.

Kleffens, Titia van; Baarsen, Berna van; Leeuwen, Evert van. (2003). The medical practice of patient autonomy and cancer treatment refusals: a patients' and physicians' perspective. *Social Science & Medicine*, In Press, Corrected Proof, Available online 8 October 2003.

Kreps, G. L.; and Kunimoto, E. N. (1994). *Effective communication in multicultural health care setting*. Thousand Oaks, CA: Sage.

Krikelas, J. (1983). Information seeking behavior: patterns and concepts. *Drexel Library Quarterly*, 19(2), P5-20.

Krohne, H. W. (1993). Vigilance and cognitive avoidance as concepts in coping research. In H. W. Krohne (Ed.), *Attention and avoidance: strategies in coping with aversiveness* (Chapter 2). H. W. Seattle: Hogrefe and Huber.

Kuhlthau, C. C. (1991). Inside the search process: information seeking from the user's perspective. *Journal of the American Society for Information Science*, 42(5), P361-371.

Labelle, R.; Stoddart, G.; and Rice, T. (1994). A re-examination of the meaning and importance of supplier-induced demand. *J Health Econ*, 13(3), Oct, P347-368.

Laine, C.; and Davidoff, F. (1996). Patient-centered medicine: a professional evolution. *JAMA*, 275, P152-156.

Larkin, M. (2000). Online support groups gaining credibility. *Lancet*, May, 355(9217), P1834.

Larner, A. J. (2003). Use of the Internet and of the NHS direct telephone helpline for medical information by a cognitive function clinic population. *International Journal of Geriatric Psychiatry*, 18, P118-122.

Leydon, GM; Boulton, M; Moynihan, C; Jones, A; Mossman, J; Boudioni, M; McPherson, K. (2000). Cancer patients' information needs and information seeking behavior: in depth interview study. *BMJ*, Apr, 320(7239), P909-913.

Leadbeater, Maria BA (Hons). (2001). Information needs of patients with cancer. *Nursing Standard*, Volume 16, Issue 3, October, P33-35.

Lee, Hur-Li. (2003). Information spaces and collections: Implications for organization. *Library & Information Science Research*, Volume 25, Issue 4, Winter, P419-436.

Luker, K. A.; Beaver, K.; Leinster, S. J.; Owens, R G.; Degner, L. F.; and Sloan, J. A. (1995). The information needs of women newly diagnosed with breast cancer. *J Adv Nurs*, 22, P134-141.

MacInnis, D. J.; and Jaworski, B. J. (1991). Enhancing and measuring consumers' motivation, opportunity, and ability to process brand information from ads. *Journal of Marketing*, 53, P1-23.

Manfredi, C; Czaja, R; Price, J; Buis, M; Janiszewski, R. (1993). Cancer patients' search for information. *Journal of National Cancer Inst Monogr*, (14), P93-104.

Marcus, S. H.; and Tuchfield, B. S. (1993). Sharing information, sharing responsibility: helping health care consumers make informed decisions. Proceedings of the Annual-Symposium on Computing Applied to Medical Care (P3-7).

Marinker, M; and Working Party. (1997). *From Compliance to Concordance: Achieving Shared Goals in Medicine Taking*. London: Royal Pharmaceutical Society of Great Britain.

Mazur, A. (1981). Media coverage and public opinion on scientific controversies. *J Commun*, 31, P106.

McConnell, D.; Butow, P. N.; Tattersall, M. H. (1999). Audiotapes and letters to patients: the practice and views of oncologists, surgeons and general practitioners. *Br J Cancer*, 79, P1782-1788.

McCreadie, Maureen; and Rice, Ronald E. (1999). Trends in analyzing access to information. Part I: cross-disciplinary conceptualizations of access. *Information Processing and Management*, 35, P45-76.

McPherson, C. J.; Higginson, I. J.; and Hearn, J. (2001). Effective methods of giving information in cancer: a systematic literature review of randomized controlled trials. *J Public Health Med*, 23, P227-234.

Mechanic, David; and Meyer, Sharon. (2000). Concepts of trust among patients with serious illness. *Social Science & Medicine*, 51, P657-668.

Meischke, H.; and Johnson, J. D. (1995). Women's selection of sources for information on breast cancer detection. *Health Values*, 19, P31-38.

Menon, Ajit M.; Deshpande, Aparna D.; Perri, Matthew III; and Zinkhan, George M. (2002). Trust in online prescription drug information among Internet users: the impact on information search behavior after exposure to direct-to-consumer advertising. *Health Marketing Quarterly*, Vol. 20 (1), P17-35.

Meredith, C.; Symonds, P.; Webster, L.; Lamont, D.; Pyper, E.; Gillis, C. R.; et al. Information needs of cancer patients in West Scotland: cross section survey of patient's views. (1996). *BMJ*, 313, P724-726.

Michielutte, R; and Diseker, RA. (1982). Racial differences in knowledge of cancer: a pilot study. *Social Science & Medicine*, 16(3), P245-252.

Miller, S. M.; and Mangan, C. E. (1983). Interesting effects of information and coping style in adapting to gynecological stress: should a doctor tell all? *Journal of Personality and Social Psychology*, 45, P223-236.

Mills, M. E.; and Davidson, R. (2002). Cancer patients' sources of information: use and quality issues. *Psychooncology*, Sep-Oct, 11(5), P371-378.

Mills, M. E.; and Sullivan, K. (1999). The importance of information giving for patients newly diagnosed with cancer: a review of the literature. *J Clin Nurs*, 8, P631-642.

Mills, M. E.; Sullivan, K. (2000). Patients with operable esophageal cancer: their experience of information-giving in a regional thoracic unit. *J Clin Nurs*, 9, P236-246.

Miranda, Giovanna F.; Vercellesi, Luisa; Bruno, Flavia. (2004). Information sources in biomedical science and medical journalism: methodological approaches and assessment. *Pharmacological Research*, 50, P267-272.

Moorman, C.; and Matulich, E. (1993). A model of consumers' preventive health behaviors: the role of health motivation and health ability. *Journal of Consumer Research*, 20, P208-228.

Morgan, C. T.; and King, R. A. (1971). *Introduction to psychology*, 4th ed. New York: McGraw-Hill.

Morris, L. A.; Tabak, E. R.; and Olins, N. J. (1992). A segmentation analysis of prescription drug information-seeking motives among the elderly. *J Pub Policy Market*, 11, P115-125.

Mossman, J.; Boudioni M.; Slevin, M. L. (1999). Cancer information: a cost-effective intervention. *European Journal of Cancer*, Volume 35, Issue 11, P1587-1591.

Murray, Elizabeth; Lo, Bernard; Pollack, Lance; Donelan, Karen; Catania, Joe; White, Martha; Zapert, Kinga; and Turner Rachel. (2003). The impact of health information on the Internet on the physician-patient relationship: patient perceptions. *Arch Intern Med.*, 163, P1727-1734.

Mystakidou, Kyriaki; Parpa, Efi; Tsilika, Eleni; Kalaidopoulou, Ourania; and Vlahos, Lambros. (2002). The families evaluation on management, care and disclosure for terminal stage cancer patients. *BMC Palliative Care*. Available at: http://www.biomedcentral.com/1472-684X/1/3 [2004, July 31]

Nair, M. G.; Hickok, J. T.; Rosco, J. A.; and Morrow, G. R. (2000). Sources of information used by patients to learn about chemotherapy side effects. *Journal of Cancer Education*, 15, P19-22.

National Cancer Alliance. *Patient-centered cancer services? What patients say.* Oxford: 6 National Cancer Alliance, 1996.

NCI (National Cancer Institute). Types of Cancer: Common Cancers. Available at: http://cancer.gov/cancer_information/cancer_type/ [2003, December 11]

Nicholson, Wanda K.; Grason, Holly A.; and Powe, Neil R. (2003). The relationship of race to women's use of health information resources. *American Journal of Obstetrics and Gynecology*, Volume 188, Issue 2, February, P580-585.

O'Connor, A. M.; Rostom, A.; Fiset, V.; and et al. (1999). Decision aids for patients facing health treatment or screening decisions: systematic review. *BMJ*, 319, P731-734.

Ohlmer, B. (1992). Effects of information technology on the data need in farm management. *Swedish Journal of Agricultural Research*, 22, P181-188.

O'Malley, AS; Kerner, JF; Johnson, L. (1999). Are we getting the message out to all? Health information sources and ethnicity. *Am J Prev Med*, Oct, 17(3), P198-202.

Papacharissi, Z.; and Rubin, A. M. (2000). Predictors of Internet use. *Journal of Broadcasting & Electronic Media*, Vol. 44(2), P175-196.

Parker, E.; and Paisley, W. J. (1966). *Patterns of adult information seeking.* Stanford, CA: Stanford University Press.

Pautler, Stephen E.; Tan, James K.; Dugas, Geoff R.; Pus, Nancy; Ferri, Melanie; Hardie, W. Robert; Chin, Joseph L. (2001). Use of the Internet for self-education by patients with prostate cancer. *Urology*, Volume 57, Issue 2, 230-233.

Pennbridge, Julia; Moya, Rita; Rodrigues, Lakeshia. (1999). Questionnaire survey of California consumers' use and rating of sources of health care information including the Internet. *Western Journal of Medicine*, 171, 302-305.

Pereira, J. L.; Koski, S.; Hanson, J.; Bruera, E.D.; and Mackey J. R. (2000). Internet usage among women with breast cancer: an exploratory study. *Clin Breast Cancer*, Jul, 1(2), P148-153; discussion P154-155.

Pettigrew K. E. (1997). The role of community health nurses in providing information and referral to the elderly: a study based on social network theory [Unpublished doctoral dissertation]. London, ON: The University of Western Ontario.

Phillips, S. A; and Zorn, M. J. (1994). Assessing consumer health information needs in a community hospital. *Bulletin of the Medical Library Association*, 82, P288-293.

Pifalo, V.; Hollander, S.; Henderson, C. L.; DeSalvo, P.; and Gill, G. P. (1997). *The impact of consumer health information provided by libraries*, The Delaware experience. Bulletin Medical Library Association, 85, P16-22.

Pruyn, J. F.; Rijckman, R. M.; van Brunschot, C. J.; and van den Borne, H. W. (1985). Cancer patients' personality characteristics, physician-patient communication and adoption of the Moerman diet. *Social Science and Medicine*, 20, P841-847.

Purcell, G. P.; Wilson, P.; Delamothe, T. (2002). The quality of health information on the Internet. *BMJ*, 324, P557-558.

Radecki, C. M.; and Jaccard, J. (1995). Perceptions of knowledge, actual knowledge, and information search behavior. *Journal of Experimental Social Psychology*, 31, P107-138.

Rainey, L. C. (1985). Effects of preparatory patient education for radiation oncology patients. *Cancer*, 56, P1056-1061.

Raupach, J. C.; and Hiller, J. E. (2002). Information and support for women following the primary treatment of breast cancer. *Health Expect*, Dec, 5(4), P289-301.

Reeder, L. G. (1982). The patient-client as consumer: some observations on the changing professional-client relationship. *J Health Soc Beh*, 13, P406-412.

Rees, C. E.; and Bath, P. A. (2000a). Mass media sources for breast cancer information: Their advantages and disadvantages for women with the disease. *Journal of Documentation*, 56, P235-249.

Rees, C. E.; and Bath, P. A. (2000b). The information needs and source preferences of women with breast cancer and their family members: a review of the literature published between 1988 and 1998. *Journal of Adv. Nurs*, 31, P833-841.

Reeves, 2000

Reynolds, P. M.; Sanson-Fisher, R. W.; Poole, A. D.; Harker, J.; and Byrne, M. J. (1998). Cancer and communication: information-giving in an oncology clinic. *Br Med J Clin Res Ed*, 282, P1449-1451.

Rimer, B. K.; Catoe, K. E.; Graves, C.; Burklow, J.; and Anderson, D. M. (1993). Older callers to the Cancer Information Service. *Journal of the National Cancer Institute Monograph*, 14, P165-169.

Roper Starch Worldwide Inc. (1997). American talk about science and medical news: The National Health Council Report. Harrison, NY.

Rosenstock, I. M. (1974). Historical origins of the Health Belief Model. *Health Education Monographs*, 2, P328-335.

Rothchild, E. (1994). Family dynamics in end-of-life treatment decision. *Gen Hosp Psychiatry*, 16, P251-258.

Rubin, A. M. (1986). Uses, gratifications and media effects research. In J. Bryant and D. Zillmann (Ed.), *Perspectives in media effects*, (P281-301). Hillsdale Nj, Lawrence Erlbaum.

Rutten, Lila J. Finney; Arora, Neeraj K.; Bakos, Alexis D.; Aziz, Noreen; and Rowland, Julia. (2004). Information needs and sources of information among cancer patients: a systematic review of research (1980-2003). *Patient Education and Counseling*, Article in process.

Sanchez, P. M. (2000). The potential of hospital website marketing. *Health Marketing Quarterly*, Vol. 18(1/2), P45-57.

Satterlund, Melisa J.; McCaul, Kevin D.; Sandgren, Ann K. (2003). Information Gathering Over Time by Breast Cancer Patients. *J Med Internet Res*, August, 27, 5(3), e15.

Savolainen, Reijo. (1995). Everyday life information seeking: Approaching information seeking in the context of "way of life". *Library & Information Science Research*, Volume 17, Issue 3, Summer, P259-294.

Savolainen, Reijo. (1999). The role of the internet in information seeking. Putting the networked services in context*1. *Information Processing & Management*, Volume 35, Issue 6, November, P765-782.

Savolainen, Reijo; and Kari, Jarkko. (2004). Placing the Internet in information source horizons. A study of information seeking by internet users in the context of self-development. *Library & Information Science Research*, Article in process. Available at: www.sciencedirect.com [April 15, 2004].

Schement, Jorge R. (1993). Communication and information. In Schement, J. R., & Ruben, B. D. (Eds.). I*nformation and behavior* (Vol. 4, P2-33). New Brunswick, NJ: Transaction.

Schement, Jorge R.; and Ruben, Brent D. (1993). *Between communication and information*. New Brunswick, NJ: Transaction Publishers.

Scott, J. T.; Entwistle, V. A.; Sowden, A. J.; and Watt, I. (2001). Giving tape recordings or written summaries of consultations to people with cancer: a systematic review. *Health Expect*, 4, P162-169.

Sharon M. Gray. (2003). A review of *Looking for Information: A Survey of Research on Information Seeking, Needs, and Behavior* (Case, Donald O. San Diego, CA: Academic Press, 2002). *Journal of Medical Library Association*, April 2003, 91(2), P259–260. Available at: http://www.pubmedcentral.nih.gov [May 20, 2004]

Sheen. (1992). Barriers to scientific and technical knowledge acquisition in industrial R. & D. *R. & D. Management*, 22, P136-143.

Shuchman, M.; and Wilkes, M. S. (1997). Medical scientists and health news reporting: A case of miscommunication. *Ann Intern Med*, 126, P976-982.

Siegel, K.; and Raveis, V. (1997). Perceptions of access to HIV-related information, care, and services among infected minority men. *Qual Health Res*, 7, P9-31.

Silberg, W. M.; Lundberg, G. D.; and Musacchio, R. A. (1997). Assessing, controlling, and assuring the quality of medical information on the Internet: Caveant lector et viewor – Let the reader and viewer beware. *JAMA*, 277, P1244-1245.

Slevin, M. L.; Nichols, S. E.; Downer, S. M.; Wilson, P.; Lister, T. A.; Arnott, S.; and et al. (1996). Emotional support for cancer patients: what do patients really want? *Br J Cancer*, 74, P1275-1279.

Slevin, M. L.; Terry, Y.; Hallett, N.; Jefferies, S.; Launder, S.; Plant, R.; Wax, H.; and McElwain, T. (1988). BACUP – the first two years: evaluation of a national cancer information service. *British Medical Journal*, 297, P669-672.

Solano, C.; Leon, H.; Perez, E.; and Herrero, M. (2003). The role of personal information sources on the decision-making process of Costa Rican dairy farmers. *Agricultural Systems*, 76, P3-18.

Sonnenwald, D. (1999). Evolving perspectives of human information behavior: Contexts, situations, social networks and information horizons. In T. D. Wilson & D. Allen (Eds.), *Exploring the contexts of information behavior, Proceedings of the 2nd International Conference on Research in Information Needs, Seeking and Use in Different Contexts, 13-15 August 1998, Sheffield, UK* (P176-190). London, England: Taylor Graham.

Spink, Amanda; and Cole, Charles. (2001). Information and poverty: information seeking channels used by African American low-income households. *Library & Information Science Research*, Volume 23, Issue 1, Spring, P45-65.

Sproull, I.; and Kiesler, S. (1991). *Connections: new ways of working in the networked organization*. Cambridge, MA: The MIT Press.

Stein, J. A. (1981). Irradiation-related thyroid cancer: influencing the health behavior of high risk individuals through mass media and a telephone information service. Paper presented to the American Association for Cancer Education, San Diego.

Stigler, G. (1961). The economics of information. *Journal of Political Economy*, 69, P213-225.

Stockler, M.; Butow, P. N.; and Tattersall, M. H. (1993). The take-home message: doctors' views on letters and tapes after a cancer consultation. *Ann Oncol*, 4, P549-552.

Street, R. L.; Voigt, B.; Geyer, C. Jr.; Manning, T.; and Swanson, G. P. (1995). Increasing patient involvement in choosing treatment for early breast cancer. *Cancer*, 76, P2275-2285.

Streptoe A.; Sutcliffe I; Allen B.; and Coombes C. (1991). Satisfaction with communication, medical knowledge, and coping style in patients with met static cancer. *Social Science & medicine*, 32, P627-632.

Sutherland, A. J.; McGregor, M. J.; Dent, J. B.; Willock, J.; Deary, I.; Gibson, G.; Grieve, R.; and Morgan, O. (1996). Edinburgh farmer decision making study: Elements important to the farmer. In: Beers, G.; Huirne, R. B. M.; and Pruis, H. C. (Eds.), Farmers in Small-scale and Large-scale Farming in a New Perspective. Objectives, Decision Making and Information Requirements. *Agricultural Economics Research Institute*, The Netherlands, P162-171.

Tardy, R. W.; and Hale, C. (1998). Getting "plugged in": A network analysis of health-information seeking among "stay-at-home moms". *Communication Monographs*, 65(4), P336-357.

Thomas, C. (1993). Deconstructing concepts of care. *Sociology*, 27 (4), P649-669.

Thomas, Carol; Morris, Sara M.; and Harman, Juliet C. (2002). Companions through cancer: the care given by informal carers in cancer contexts. *Social Science & Medicine*, 54, P529-544.

Thomas, R.; Daly, M.; Perryman, B.; and Stockton, D. (2000). Forewarned is forearmed – benefits of preparatory information on video cassette for patients receiving chemotherapy on radiotherapy: a randomized controlled trial. *Eur J Cancer*, 36, P1536-1543.

Thompson, A.D.; Simonson, M.R.; and Hargrave C.P. (1992). Educational technology: a review of the research, Washington DC: Association for Educational Communications and Technology.

Timko, M.; and Loyns, R. M. A. (1989). Market information needs for Prairie farmers. *Canadian Journal of Agricultural Economics*, 37, P609-627.

Toggerson, S. K. (1981). Media coverage and information seeking behavior. *Journalism Quarterly*, 58, P89-93.

Turk-Charles, S.; Meyerowitz, B. E.; and Gatz, M. (1997). Age differences in information seeking among cancer patients. *International Journal of Aging and Human Development*, 45(2), P85-98.

Van Zuuren, F. J.; and Wolfs, H. M. (1991). Styles of information seeking under threat: personal and situational aspects of monitoring and blunting. *Personality and Individual Differences*, 12, P141-149.

Vanderbilt Ingram Cancer Center (VICC). (2003). Facts at A Glance. Available at: http://www.mc.vanderbilt.edu/vicc/showcontent.php?id=14 [September 14, 2004].

Verble, M.; and Worth, J. (1996). The case against more public education to promote organ donation. *J Transpl Coord*, 6, P200.

Ward, J. A.; Anderson, D. M.; Pundik, C. G.; Redrick, A.; and Kaufman, R. (1993). Cancer Information Service utilization by selected US ethnic groups. *Journal of the National Cancer Institute Monograph*, 14, P147-156.

Weigts, W.; Widdershoven, G.; Kok, G.; and Tomlow, P. (1993). Patients' information seeking actions and physicians' responses in gynecological consultations. *Qualitative Health Research*, 3, P398-429.

Wellman B. (1995). Lay referral networks: using conventional medicine and alternative therapies for low back pain. *Res Soc Health Care*, 12, P 213-238.

Whelan, T. J.; Mohide, E. A.; Willan, A. R.; and et al. (1997). The supportive care needs of newly diagnosed cancer patients attending a regional cancer center. *Cancer*, 80, P1518-1524.

Whelan, T. J.; Rath, D.; Willan, A.; and et al. (1998). Evaluation of a patient file folder to improve the dissemination of written information materials for cancer patients. *Cancer*, 83, P1620-1625.

White, M. D. (2000). Questioning behavior on a consumer health electronic list. *Library Quarterly*, 70, P302-334.

Wilson, T. D. (1997). Information behavior: an interdisciplinary perspective. *Information Processing & Management*, Vol. 33, No. 4, P551-572.

Wilson, T. D. (1994). Information needs and uses: fifty years of progress? In B. C. Vickery (Ed.). *Fifty years of information progress: a journal of Documentation review* (P15-51). London, Aslib.

Wilkinson, G. S.; and Wilson, J. (1983). An evaluation of demographic differences in the utilization of a cancer information service. *Social Science & Medicine*, 17(3), P169-175.

Witte, K.; Stokols, D.; Iturate, P.; and Scheander, M. (1993). Testing the health belief model in a field study to promote bicycle safety helmets. *Communication Research*, 20, P564-586.

Worsley, A. (1989). Perceived reliability of sources of health information. *Health Education Research*, 4, P367-376.

Yeager, KA; Miaskowski, C; Dibble, S; Wallhagan, M. (1997). Differences in pain knowledge in cancer patients with and without pain. *Cancer Practice*, Jan-Feb, 5(1), P39-45.