

MEDICAL INFORMATION SOURCES FOR CANCER PATIENTS:

HEALTH CARE PROVIDERS PERSPECTIVE

SIDDHARTH RAI

Thesis under the direction of Professor David M. Dilts

Majority of Americans are paying moderate or a great deal of attention to medical health news. The ability to clearly determine patients' past and potential medical information sources can help both physicians and patients make more efficient medical decisions, but limited study has been done to identify health care providers' attitude about their patients' use of this data. A survey was implemented at the Vanderbilt Ingram Cancer Center, Nashville, TN. Of the 110 individuals approached, 66 (60%) completed the questionnaires. Almost 90% health care providers expected patients to gather information from human sources, even though the quality of information obtained from some of those sources, particularly friends, relatives and acquaintances was poor (2.68 of 7). Patients were recommended to limit using friends, relatives and acquaintances as sources of information. The quality of information obtained from various sources was consistently rated lower by health care providers than patients. Health care providers felt that certain patient demographics are good predictors for cancer information source preferences.

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SIDDHARTH RAI

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David M. Dilts

Barbara Murphy

DEDICATION

To my entire family and Aparna

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CHAPTER I

INTRODUCTION

Cancer is a serious human health issue (Junghans et al, 2004), and it is the second leading cause of death in the USA, exceeded only by heart disease (ACS, 2004a). In 2000, 1,220,100 people in the United States were diagnosed with cancer for the first time and 563,100 died of some form of this disease (ACS, 2004b). The diagnosis of cancer gives rise to uncertainty, fear and loss, which can be alleviated by communication and information (Fallowfield et al, 1990). Effective communication and appropriate information offered at the right time (Mills & Davidson, 2002) are known to be key to optimal health outcomes.

Information is seen as crucial for treatment and rehabilitation, by relieving anxiety and promoting a sense of control (Balmer, 2005). 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.

To date, most studies of patients' information needs have been conducted on cancer patients and their use of various sources to gather health information (Mills & Davidson, 2002). There is no in-depth information about the effects of information on clinical setting and almost no information regarding oncologists' attitude towards their patients' use of such information. Therefore it is important to discover health care provider's perspective of the various sources of medical information used by patients to gather information.

Thesis Objectives

The objectives of this study are to investigate: 1) health care professionals view of the various sources of information patients use to gather information; 2) health care professionals views of the quality of information gathered by cancer patients from various sources; 3) the sources of information health care professionals recommend patients to utilize ; 4) the expected quality of information from the sources recommended by the health care professionals; 5) health care professionals views on whether patients demographics can be used as a predictor for medical information source preferences; and 6) the views of the patients and health care professionals about the past and future sources of medical information and the quality of information gathered from those sources.

A survey was implemented at Vanderbilt Ingram Cancer Center and Vanderbilt Ingram Cancer Center Affiliate Network (VICCAN) conferences. There were three parts in this survey: Part A investigates the demographic information of the health care professionals. Part B investigates participants' perspective of the medical information sources visited by cancer patients in the past and potential medical information sources in the future. Part C investigates the perceived benefits of information in decision making. Emails were sent prior to the study seeking health care professionals'.

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 medication information sources, patient demography and the impact of information obtained from various sources on the clinical setting. Hypotheses are developed in this section, based on the review of the literature. The third section develops the measurement instrument to test the hypotheses developed in second section. The hypotheses are investigated using a survey methodology that is

described in detail in the fourth section. The fifth section statistically analyzes the data and discusses the results. The sixth section, the discussion and conclusion 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

More than 75% of the Americans are paying moderate or a great deal of attention to medical health news and they are turning more frequently to the Internet to obtain health information (Helft et al, 2003). Although, there is an increasing amount of published information about sources of patient obtained medical information for diseases such as heart failure(Gwadry-Sridhar et al, 2003) and AIDS (Buseh et al, 2002), there are only a limited number of studies investigating the views of cancer patients (Mills and Davidson, 2002).

There have been studies done with cancer patients to identify the sources of patient obtained medical information (POMI) (Kakai et al 2003; Basch et al 2004), the quality of the information obtained (Mills & Davidson, 2002), the future sources of POMI (James et al, 1999), the predictors of the information seeking behavior (Mills & Davidson, 2002) and the effect of POMI on the clinical setting (Helft et al,2003). However, there are little in-depth data about the effect of information obtained from patients in the clinical setting and almost no information regarding US oncologists' attitudes about their patients' use of this data (Helft et al, 2003). The ability to clearly determine patients' potential medical information sources can help both physicians and patients make more efficient medical decisions (Dranove 1988; Labelle et al 1994; Kleffens et al 2003; Basch et al, 2004). My study investigates the physicians' views on the POMI sources in order to fill this gap.

This literature review is divided into five sections: 1) importance of information for cancer patients; 2) medical information source preferences; 3) POMI in clinical setting and

physicians' view of the POMI; 4) perceived quality of POMI and 5) predictors of information seeking behavior.

Importance of information for Cancer Patients

Cancer causes 1 of every 4 death in the USA (ACS, 2004a). Half of all men and one-third of all women in the USA will develop cancer during their lifetimes (ACS, 2004b). The impact of this disease has remained far-reaching. "You have cancer," these words almost always cause devastation in the lives of their recipients (Arora, 2003). Feelings of uncertainty about and loss of control over one's life are common reactions (McWilliam et al., 2000). Certainly for the patients themselves, there are profound psychological, physiological, and economic outcomes associated with the diagnosis and treatment of cancer and its symptoms (Ashbury et al., 1998). The diagnosis of cancer is associated with substantial anxiety about prognosis, the availability and effectiveness of treatments and their side effects, and a lack of long-term disease control in many cases (Chen & Sui, 2001). In fact, the anxiety among cancer patients associated with possible death, disfigurement, and disability is often greater than that among patients with other illnesses (Takayama et al., 2001).

The diagnosis of cancer gives rise to many fears and misconceptions, and information is vital in building accurate representations of cancer (Sainio & Eriksson, 2003). Cancer is a life-threatening illness and it is crucially important that patients receive honest and adequate information about their condition (Stephens et al. 1991). Information can play an important role in the successful treatment and rehabilitation of cancer patients (Lauri and Sainio, 1998), particularly because cancer patients today often make a full recovery, or at least live many years with the disease (Thorne, 1999). Also, information can improve the quality of life of a cancer

patient by minimizing the impact of the disease and treatment on patients' functioning and well-being (Arora et al., 2003). The lack of adequate information can have adverse effects such as dissatisfaction, reduction in patient wellbeing and distress in patients and their families (Fallowfield et al, 1990).

Information can help cancer patients to cope with the disease (Stephoe et al. 1991), to control the situation (Hack et al. 1994), to manage the disease and in comforting the patient (Galloway et al. 1997). Lack of information leads to increased uncertainty, anxiety, distress, dissatisfaction and can negatively influence patients treatment decisions (Beaver et al, 1999). Information is crucial to patients when they participate in decision-making concerning their care (Sainio & Eriksson, 2003). Having sufficient information about illness and available treatment options is a necessary precondition for active involvement in treatment decision-making (Pinquart & Duberstein, 2004). To make informed decisions, cancer patients and their families desire information about their diagnosis and prognosis, conventional and alternative therapeutic options, risks and benefits of treatment, and relevant experimental therapies (Chen & Sui, 2001). In general, receiving information about their chance of cure and spread of disease are the patients' top priorities (Pinquart & Duberstein, 2004).

Patients are more aware than they have been in the past about experimental and alternative therapies (Chen & Sui, 2001). More than 75% of Americans reported that they paid a moderate amount or a great deal of attention to medical and health news (Helft et al, 2003). This desire for information is also reflected in the survey conducted by Chen & Sui (2001), with 86.4% of patients reporting that they desired as much information as possible about their illness.

Medical Information Source Preferences

In their pursuit to gather information, patients refer to various sources of health information (Kakai et al., 2003). Cancer patients consider healthcare providers to be the primary source of such information, especially physicians (Silliman et al., 1998). At the same time, studies have also reported limitations in physicians' information giving behavior that often result in cancer patients leaving the medical visit confused and unsure about several aspects of their disease and its treatment (McWilliam et al 2000; Quirt et al 1997). This is a complex issue, but oncologists in busy clinical practices often have limited time to spend with each patient, and communication may have a lower priority than medical treatment (Chen & Sui, 2001). As a result, patients whose need for information is not satisfied by the healthcare providers turn to other sources of information (Carlsson, 2000). Since information source preferences have a strong impact on patients' decision making, it is important to know where cancer patients go for Patient Obtained Medical Information (POMI) (Kleffens et al, 2003).

The factors that first enter into people's assessment and choice of information sources are usually tangible, such as whether the source is oral or written, human or virtual, in-house or external, as well as whether lay or authoritative, easily accessible or hard to get at, and whether the source contains information or pointers to information (Hertzum et al, 2002). The choice of information sources can be classified by different types of media, that is, print-based (e.g., books, newspapers, and magazines), broadcast (e.g., radio, TV, and movie), human (e.g., friends, physicians, and patients), and organizations (e.g., NIH and HMO). For today's medical field, information sources not only include traditional media discussed above, but also newer media to facilitate the passage of information (Jefford and Tattersall, 2002; Hertzum et al, 2002). For example, many telephone services (helpline) enable patients to seek emotional support in addition

to specific medical information. With the advancement of information technology, the use of the Internet as a source of health information has been increasing, particularly among cancer patients with higher education and younger age (Elliott & Elliott 2000; Kakai et al 2003). In a study conducted by Pew Research Center in 2003 it was found that 55 million Americans sought health information on the Internet and more than half of patients who actively search for information on the Internet sometimes question their oncologists' advice or recommendations (Helft et al, 2003). The Internet is changing the doctor-patient relationship as it provides patients with the potential to make better health decisions due to ease in access to vast amounts of health information (Sciamannaa et al, 2003).

To summarize, the information gathered from the different sources of POMI helps cancer patients to cope up with disease, manage disease better and get actively involved in medical decision making. The sources of information that have been identified for the purpose of this study have been categorized in Table 1. A complete list of sources with citations has been included in the "Development of the Instrument" chapter.

POMI in Clinical Setting and Physicians view of POMI

The revolution in health care information has great potential to impact the way that patients interact with their physicians. For example, it is quite likely that 1 hour of Internet searching by an intelligent patient on a reputable website can give the patient information about his or her condition that the physician is not aware of (Ferguson, 2002). When patients attempt to discuss such information with their physicians, most patients (88.3%) found that their physicians were willing to discuss information found in the media or on the Internet, and 67.3% of patients found that their physicians spent a lot (16.4%) or a moderate amount (50.9%) of time discussing this information

Table 1: Sources Included in Each Source Type

Human Sources	<ul style="list-style-type: none"> I. Physician or Physician’s Assistant II. Nurse or Other Health Professionals III. Support Group IV. Other Patients V. Relatives, Friends and Acquaintances VI. Narratives
Printed media	<ul style="list-style-type: none"> I. Medical Leaflets or Pamphlets II. Books III. Medical Journals IV. Newspapers/ Magazines
Networked Sources	<ul style="list-style-type: none"> I. Email (Physician, Nurse, Support Group, Patients and other Healthcare Professionals) II. Internet or Medical Websites III. Telephone or Helpline
Organizational sources	<ul style="list-style-type: none"> I. Educational Programs by HMO or Hospital II. National/Local Medical Information Sources
Broadcast media	<ul style="list-style-type: none"> I. TV/Radio II. Films/Movies
Other sources	<ul style="list-style-type: none"> I. Audio/ Video Tapes

with them (Chen & Sui, 2001). However, physicians cannot assume that patients will volunteer all relevant information (Arora, 2003). In fact, cancer patients are reluctant to disclose their psychosocial concerns, and often believe that experience of problems such as depression, fatigue, pain, etc. are inevitable consequences of their disease and its treatment (Bakker et al., 2001). They may feel that there is no point mentioning such issues to the physician as nothing can be done. This avoidance on the part of patients is reinforced by the reluctance of physicians to inquire actively about patients’ concerns and feelings (Ford et al., 1996). In an analysis of physicians’ knowledge about their patients’ preference revealed that physicians did not know their patients’ preferences for involvement in making health decisions (Rothenbacher et al. 1997).

Researchers have held deficiencies in physicians’ communication (Ford et al. 1996) and interpersonal skills (Arora, 2003) accountable for unsuccessful information exchange between

patients and physicians. Throughout the last 25 years, a number of authors have focused on communication skills in the consultation (Stevenson et al., 2000). The importance of communication skills has long been acknowledged in general practice training (RCGP, 1972), while the need to teach communication skills formally, as part of British undergraduate medical education has also been recognized as an important part of the curriculum (General Medical Council, 1993). Prior to imparting information, physicians have been recommended to actively listen to patients' story without interruption and spent a large proportion of time during visits in information exchange (Simpson et al., 1991).

Yet, despite the advocacy of the use of patient-centered strategies, the data suggests that this does not seem to be happening in practice (Stevenson et al., 2000). For example, on examining physicians' ability to elicit a patient's complete set of concerns found that only 28% of physicians elicited the patient's complete agenda (Frosch & Kaplan, 1999). In all other cases, the patients were "redirected" or "interrupted" before they could finish voicing their concerns, leading to overall fewer patient concerns being spelled out, other concerns arising late in the encounter, and important information not being gathered. Interestingly, while patients in this study were redirected after an average of 23.1 seconds, those patients who were not redirected required an average of only 32 seconds to voice their concerns (Frosch & Kaplan, 1999).

All the above mentioned studies conducted on the communication behavior between patients and physicians suggest that physicians continue to under-estimate both their problems in communicating and their patients' level of distress (McWilliam et al 2000). Even though patients and physicians have been jointly participating more to reach to a decision, physicians do not have a clear understanding of patients' preferences for his or her involvement in the shared decision making, the patients' level of distress or patients concerns and feelings (Rothenbacher et

al. 1997). It could be stated that the successful information exchange is not always taking place between physician and the patient, hence it is possible that physician might not have a clear understanding of patients' knowledge.

Though several studies have examined the quality of medical information and the type of medical information being searched for, little work has been done to evaluate information's possible impact in the clinical setting (Purcell et al 2002; Gagliardi & Jadad 2002; Wilson 2002). There is no information regarding physicians' attitude about their patients' use of medical information (Helft, 2003). My study investigates the physicians' attitude towards the information gathered by patients from different sources. However, from the detailed discussion above, it was determined that it is possible that physicians might not have a clear understanding of patients' knowledge of treatment or of the information gathered by patients from sources of POMI. I therefore hypothesize

H1: Physicians perception about sources of POMI for cancer patients have used will be different from the sources of POMI patients actually prefer (Patient Past vs. Physician Past).

The judgments drawn from prior experiences of using various information sources have an impact on the future use of information sources (Hertzum et al., 2002). However, there is no published study asking patients or physicians about the potential sources they will go in future. My colleague Chen Wang, under the guidance of Dr. Dilts is investigating the potential sources of POMI patients will go in the future I will be investigating the sources of POMI physicians recommend their patients to visit in the future. Based on previous discussions I hypothesize that

H2: Physicians recommendation for the future sources of POMI will be different from cancer patients' preference of the same (Patient Future vs. Physician Future).

Quality of POMI

Good decision-making that takes into account medical best-evidence and individual patient factors requires high quality information which includes detailed explanations about the patient's condition, and risks and benefits of different treatment options (Godolphin et al., 2001). Poor reporting of medical information often raise false hopes in patients and their families and results in unrealistic expectations (Chen & Sui, 2001).

As discussed earlier, physicians and other healthcare providers have been the primary source of cancer related information. But, if patients do not get sufficient information from healthcare providers, they rely on other sources to satisfy their need medical information (Chen & Sui, 2001). Unfortunately, much of the information materials available are of poor quality and are often inaccurate or misleading (Solano et al 2003; Coulter 2003). Especially, the advent of Internet has provided a gateway to an abundance of questionable information (Junghans, 2002). With no rules or regulations on the posting of medical and health information on the Internet, the quality of information is quite variable (Chen & Sui, 2001). Therefore, it is important to know patients and physicians view of the quality of information gathered from various information sources.

Some studies have been conducted investigating the quality of information obtained from the preferred sources (Basch et al, 2004; Mills & Davidson, 2002). Among those limited studies, most were done on patients outside US, such as Canada (Godolphin et al 2001; Chen & Sui, 2001) Ireland (Mills & Davidson, 2002) and Sweden (Nillson-Ihrfelt et al, 2004). Basch et al's (2004) study was done on cancer patients in US, but it is limited to comparison between electronic and non-electronic sources. There are fewer studies that have asked physicians about the quality of medical information obtained from different sources (Helft et al., 2003; Chen &

Sui, 2001). Moreover, there is no survey that has asked physicians about the quality of information patients obtained by patients from POMI. Therefore it is important for the present study to discover physicians' perspective of the quality of POMI.

In the study of cancer patients and physicians in Canada, Chen & Sui (2001) investigated the views of patients and physicians about the quality of health information available. Most oncologists felt that the media reported accurate medical information only sometimes (60.6%) or rarely (23.8%). However, only 43% patients felt that the media reported accurate medical information. This suggests a difference in the perception of patients and physicians about the quality of health information from the same source. This is the basis for following hypothesis:

H3: Physicians perception about the quality of POMI used by cancer patients will be different from the patients' view of the same (Patient Past vs. Physician Past).

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). However, it is not known if cancer patients will continue going to sources where they believed the quality of information obtained was above average, and will discontinue gathering information from sources where they believed the quality of information obtained was below average. Since there is no study asking patients or physicians about the expected quality of information from the sources they will go in future, Chen Wang, under the guidance of Dr. Dilts is also investigating the quality of information expected from potential sources of POMI patients will go in the future. Also, no study has been conducted on physicians to find out the quality of information expected from the recommended sources of information. My study investigates physicians' view of the expected quality of information from recommended sources and also compares it with patients' view of the expected quality of information from those sources.

H4: Physicians perception of the expected quality of information from future sources of POMI will be different from cancer patients' perception of the same (Patient Future vs. Physician Future).

Predictors of Information Seeking Behavior

Several studies have indicated that there are predictors of information seeking behavior of cancer patients (Blanchard et al, 1988; Derdiarian, 1987). For example, educational background may influence people's health information-seeking behavior in combination with ethnicity (Carlsson, 2000), although all ethnic groups perceive healthcare professionals as the most helpful source of information (Pennbridge et al., 1999). The significant influences of culture on health behaviors due to different set of values, beliefs, attitudes and behaviors of each group have been discussed (Kakai et. al, 2003). Furthermore, research has shown that patients' personality, demographic characteristics and level of knowledge all influence the extent to which professionals decide to give information to their patients (Veronesi et al. 1999). An international survey of women with cancer (n=1932) showed that patients with a higher level of knowledge received more information from staff members than did patients with less knowledge (Veronesi et al. 1999).

Demographics may influence information seeking preference of patients (Mills & Davidson, 2002). The factors pointed out by researchers as the predictors of information seeking and used for the purpose of this study include gender, age, race, education, working status, household income, computer access, insurance coverage and general health condition (Kakai et al 2003; Jefford & Tattersall 2002; Mills & Davidson 2002; Kreps & Kunimoto 1994).

Table 2: Factors that Influence Cancer Information Seeking

Variables	Reference
Gender	Carlsson (2000), Mills & Davidson (2002), O'Malley et al (1999)
Age	Carlsson (2000), Mills & Davidson (2002), O'Malley et al (1999), Pennbridge et al (1999)
Race	Guirdy et al (1998), Kakai et al (2003), O'Malley et al (1999), Ward et al (1993)
Education	Carlsson (2000), Guirdy et al (1998), Kakai et al (2003), O'Malley et al (1999), Ward et al (1993)
Working status	Kreps & Kunimoto (1994)
Household income	Diaz et al (2002), Johnson et al (2001)
Computer Access/Use	Basch et al (2004)
Insurance Coverage	O'Malley et al (1999)
General Health Condition	Fox & Rainee (2000) & Satterlund et al (2003)

Thus, the ability to clearly determine patients' potential medical information sources preferences can help physician and patients make more efficient and effective joint decisions (Dranove 1988; Labelle et al 1994; Kleffens et al 2003; Basch et al, 2004). However, since physicians dedicate limited time to each patient (Chen & Sui, 2001) and are not always able to develop great rapport and feeling of openness with the patient (Arora, 2003), it is not clear if enough information is transferred from patients to physicians. This is the basis my hypothesis that

H5: Physicians perception about the predictors of information seeking behavior of cancer patients will be different from the results of analysis of data on patients.

Conclusion from the Literature review

Americans are turning more frequently to various sources of health information to gain knowledge about their illness Hence, it is important to understand the effect of patient obtained medical information (POMI) in the clinical setting.

To ensure active involvement and quality outcome physicians should have a clear understanding of patients' knowledge and preferences. Therefore, it is important to understand physicians' view of the sources where patients receive information from, the quality of POMI from those sources, the POMI sources physicians recommend patients, the expected quality of such sources and the impact of patients demographics on information seeking behavior.

An extensive review of the literature indicates that the amount of research done to investigate all of the above mentioned topics is little. Moreover, there has been no study that investigates the sources of information physicians recommend to their patients to obtain medical information and the expected quality of the medical information from those sources. Therefore, research needs to be done to investigate the views of physicians about the sources of patient obtained medical information.

CHAPTER III

DEVELOPMENT OF THE INSTRUMENT

With the purpose to test the hypothesis developed in the Chapter II, I developed the operational instrument based on the literature review and pretest.

Instrument from Literature review

From the review of the literature, two major areas: patient obtained medical information (POMI) and the demographics (which act as the predictor of information seeking behavior of patients), which were discussed extensively in the previous chapter were identified for the instrument. Also discussed in the previous chapter was the list of appropriate variables for the purpose of this study for both the major areas. The list of these variables was built with their corresponding references and can be found in the latter part of this chapter.

Patient Obtained Medical Information Source Variables

Cancer patients consider healthcare providers to be the primary source of such information, especially physicians (Silliman et al., 1998). However, they use wide range of health information to gain knowledge (Cassileth et al 1980; Fallowfield et al 1994).

From the literature review we have included the following variables as the sources of medical information: 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, newspaper, magazines, audio/video tapes, films and chat-room (**Table 3**).

Demographic Variables

Based on the literature review, the variables that we have included are found in table 2, chapter II and include demographic factors influencing the information seeking behavior are as follows: gender, age, race, educational level, working status, household income, computer access, insurance coverage and general health condition

Table 3: Sources of Patient Obtained Medical Information with Citation.

Human Sources	Physician or Physician's Assistant	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)
	Nurse or Other Health Professionals	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)
	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)
	Relatives, Friends and 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)
	Narratives	Carlsson (2000), James et al (1999), Kakai et al (2003), Mills and Davidson (2002)
Printed media	Medical Leaflets or 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)
	Books	Carlsson (2000), James et al (1999), McCreadie and Rice (1999), O'Malley (1999), Pennbridge et al (1999)
	Medical Journals	Diaz et al (2002), O'Malley (1999)
	Newspapers/ Magazines	Carlsson (2000), Cohn et al (2003), Diaz et al (2002), James et al (1999), McCreadie and Rice (1999), O'Malley (1999)
Networked Sources	Email (Physician, Nurse, Support Group, Patients and other Healthcare Professionals)	Fox and Fallows (2003), McCreadie and Rice (1999)
	Internet or 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)
	Telephone or Helpline	Carlsson (2000), Horrigan et al (2000), Kakai et al (2003), Pennbridge et al (1999)
Other Sources	Audio/Video Tapes	James et al (1999), McCreadie and Rice (1999), Pautler et al (2001)
Broadcast media	TV/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)
	Films/Movies	James et al (1999), McCreadie and Rice (1999)
Organizational sources	Educational Program by HMO or Hospital	Diaz et al (2002), Pennbridge et al (1999)
	National/Local Medical Information Sources	Leadbeater (2001), Mossman et al (1999)

Development of Questionnaire & Pre-Test

The questionnaire is divided into five sections: “Letter of Confidentiality”, “Instructions”, Part A “Background Information” and Part B “Medical Information Sources” and Part C “Information Benefits”. The total length of the questionnaire is 6 pages. Two different formats of this version was developed: 1) Paper Based, which can be filled by the participants by hand and 2) Web Based, which can be filled by the participants and returned back to the investigators over the Internet.

Pre-test

The questionnaire developed for the purpose of the study was subjected to two pretests to ensure that participants are able to understand the questions. Feedback was incorporated in the latter versions of the survey.

The first pretest was distributed to 10 faculty, staff and graduate students. The participants were encouraged by the investigators to identify faults, suggest changes, and write down any doubts or suggestions about all the aspects of the questionnaire including questions, instrument and formats.

The investigator monitored and measured the time needed to answer the questionnaire. The average time to answer the survey was 6 minutes. Several problems related to clarity of the questions were reported by the respondents. The changes recommended in the pretest were incorporated in the third version of the questionnaire.

The second pretest was distributed to 12 graduate students. The average time to answer the survey remained 6 minutes. Only minor problems were identified and minute change in

formatting was recommended by the participants. The changes recommended in the pretest were incorporated.

CHAPTER IV

METHODOLOGY

The survey was implemented at Vanderbilt Ingram Cancer Center and Vanderbilt Ingram Cancer Center Affiliate Network (VICCAN) conferences, which will be explained in detail in the latter part of the chapter. The subject population for this survey was practicing oncologists at the Vanderbilt Ingram Cancer Center and oncologists, research nurses and other care providers at the VICCAN conference. Email was sent to all the oncologists at Vanderbilt Ingram Cancer Center introducing them to the study and requesting for participation. Dr. Dilts is a member of VICCAN and participates in its conferences. The investigators presented the information letter to the members and described to them the purpose of the study. The inclusion criteria for the study were oncologists, research nurses and other active cancer health professionals. There is no risk for the participants to answer the questionnaire. The type of data is mainly quantitative, not linked to specific individuals. There are no identifiers on the survey and none will be collected.

To implement the survey, IRB approval (**IRB# 040295**) was received.

IRB Approval and Amendment

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

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 the one of only 38 National Cancer Institute-designated Comprehensive Cancer Center in 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 cancer care by U.S News world report, and it is the first center to have faculty simultaneously leading three major nation 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). The number of physicians dedicated to treating cancer patients at VICC is approximately 80 (<http://www.mc.vanderbilt.edu/vicc/doclist.php>). This study was implemented using the oncologists of the Henry – Joyce Cancer Clinic at Vanderbilt.

Additionally, the study was conducted at the conferences held by Vanderbilt Ingram Cancer Center Affiliate Network (VICCAN). The Vanderbilt-Ingram Cancer Center Affiliate Network (VICCAN) was formed in 1994 to provide community oncologists and patients easier access to clinical trials. The network now includes 12 institutions within Tennessee, Kentucky and Georgia. The conferences held by VICCAN are attended by oncologists, nurses, research

administrators and other health professionals. This study was also implemented at a VICCAN conference.

Pilot Study

With the approval from the IRB and the organizers of VICCAN conference, a pilot test was implemented. The oncologists and other care providers participating in the conference were recruited for the study. A total of 13 cancer care provider were interviewed.

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

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 from the Vanderbilt Ingram Cancer Center and VICCAN conference. Email was sent to the oncologists introducing investigators to the participants, presenting the information letter, and describing the study. Oncologists were asked if they are interested in participating. Survey was sent only to those oncologists who gave approval for their participation in the study.

The recruitment at the VICCAN conference was conducted in a similar manner. Email was sent in advance to all the members of the conference introducing investigators to the participants, presenting the information letter, and describing the study. Questionnaires were given only to the interested care providers at the conference.

CHAPTER V

RESULTS AND ANALYSIS

This chapter is in two parts; the first deals with a brief description of the sample demographics and the second with hypothesis testing.

All data were coded and entered into a database using SPSS (SPSS for Windows Release 11.01.1; SPSS Inc.). Missing responses, responses that did not fit into one of the specific item responses, and items in which subjects provided more than one response to a survey item were all considered missing. Prior to starting any analysis, data were checked to confirm that there were no data entry errors.

Descriptive statistics are reported as proportions. To compare the demographic characteristics among different health care professionals (oncologists, nurses etc.), Chi-square tests were run for nominal variables (such as gender) and ordinal values (such as age group) (Mills & Davidson, 2002). Due to ordinal nature of the data, Chi-square tests were run to identify the relationship between the demographics of the respondents and the sources of POMI (Mills & Davidson, 2002).

To compare the population mean score for quality of information obtained from different sources of health care professionals and patient, independent sample t-Tests were conducted.

Sample Demographics

Of the 110 individuals approached, 66 (60%) completed and returned the survey questionnaires. Out of 66 respondents 42 were oncologists, 17 oncology nurses, 2 research nurse and 5 other health care professionals. Demographics for responding subjects are listed in **Table 4**.

The 66 physicians and other health care professionals treated 25 different kinds of cancer, and were divided up into seven different categories of cancer: Breast Cancer, Gastro Intestinal Cancer (G.I.), 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 age and years of practice, we categorized them into six and seven groups respectively for analysis purpose.

From **Table 4**, we can see that there is a well balanced number of respondents from each gender (Male= 51.5%; Female= 48.5%). Other than those, respondents seem to be oncologists (63.6%), between age 31-50 (74.6%), with 6-20 years of experience (64.4%), using Internet to gather medical information (92.4%), mostly practicing in either in urban location (30.3%) or metropolitan area (56.5%) and practicing in medical school (50.0%). The type of cancer respondents frequently treated varied from Head & Neck (4.5%) to Lung (28.8%).

To compare the demographic characteristics among different health care professionals (oncologists, nurses etc.), the Chi square tests (**Table 5**) show that on the whole, there is no significant difference among health care professionals for years of practice, type of cancer frequently treated and use of Internet. But, there are differences in age ($P=.014$), geographic location of setting ($P=.009$), type of practice setting ($P=.000$) and gender ($P=.000$). The average age of the oncologists was 44.65 years (standard deviation= 7.8 years), 13.2 years of practice (standard deviation= 7.7), 78.6% were males and 69.0% practiced in a metropolitan area. The

average age of the oncologist nurse was 47.2 (standard deviation=9.2), 21.4 years of practice (standard deviation= 9.5), 100% were females and 29.4% practiced in a metropolitan area and 3) the average age of other health care professionals was 36.0 (standard deviation=8.9), 7.8 years of practice (standard deviation= 3.3), 85.7% were females and 42.9% practiced in a metropolitan area.

Chi-square tests also showed that there were no significant differences in demographics between the health care professionals treating different types of cancer (**Table 6**).

In summary, health care professionals by different types of cancer treated have similar characteristics. However, there are some distinctive demographic characteristics between different health care professionals. The effect of these differences on health care professionals' view of sources of POMI has also been discussed along with hypothesis testing.

Hypothesis Testing

After completing the sample demographics analysis, data were analyzed to test the hypotheses formulated. Before testing the hypothesis, results from Chen Wang's study on POMI (patients view) was sought. Since the population of this study was health care professionals, results and data from Chen Wang's study was used to compare the outcomes with patients' preference.

Frequency tests were run for all the POMI sources to compare the differences between the views of patients and health care professionals. Z-tests were run to compare and determine if there was a significant difference between the proportions of "yes" between the physicians and patients. T-tests were used for the same purpose when sample size was less than 30 for any item.

Hypothesis 1

The first hypothesis proposed that health care professionals' perception about sources of POMI for cancer patients have used will be different from the sources of POMI patients prefer.

On the whole, the two most frequently used sources as viewed by both health care professionals and patients were talking with physician or physician's assistant and talking with nurse or other health professionals. There were differences in the views of health professionals and patients on the usage of other sources: 1) healthcare professionals ranked the frequency of talking with other patients, Internet/medical websites, talking with a support group, national/local medical information services, email from relatives/friends/acquaintances, email/chat room with a support group, educational program by HMO/hospital, telephone/helpline, email/chat room with other patients at least one rank higher than compared to the patients 2) healthcare professionals ranked the frequency of talking with relatives/friends/acquaintances, medical leaflets/pamphlets, books, narratives(written stories by other patients), Audio/video tapes, medical journals, films/movies, email from physician or physicians' assistant and email from nurse/other health professionals at least a rank lower than patients and 3) newspapers/magazines and TV/radio were ranked the same by both health care professionals for the frequently used source (**Table 7**).

On average human, networked and organizational sources were ranked higher by healthcare professionals where as printed media and broadcast media were ranked lower by healthcare professionals (**Table 8**).

To further test whether there are significant differences between health care professionals and patients Z-test was run for the comparison between "yes" proportions of physicians and patients. There were significant differences ($P=.0000$) in the proportion for all the sources except for talking with physicians or physicians' assistant ($P=0.4090$) (**Table 8**).

Comparison of the analysis for both the groups (physicians and patients) supports the hypothesis 1 for a majority of sources.

Hypothesis 2

The second hypothesis proposed that health care professionals' recommendation for the future sources of POMI will be different from cancer patients' preference of the same (Patient Future vs. Physician Future).

On the whole, the two frequently used sources as viewed by both health care professionals and patients were talking with physician or physician's assistant and talking with nurse or other health professionals. There were differences in the views of health professionals and patients on the usage of other sources: 1) healthcare professionals ranked the frequency of usage of national/local medical information services, medical leaflets/ pamphlets, talking with a support group, Internet/medical websites, audio/video tapes, email from physician or physicians' assistant, telephone/helpline, email from nurse/other health professionals, email/chat room with a support group, email/chat room with other patients at least one rank higher than compared to the patients, 2) healthcare professionals ranked the frequency of usage of educational program by HMO/hospital, books, talking with other patients, talking with other patients, talking with relatives/friends/acquaintances, newspaper/magazines, narratives(written stories by other patients), TV/radio and email from relatives, friends, acquaintances, films/movies at least one rank lower than the patients and 3) medical journal was ranked the same by both health care professionals for the frequently used source (**Table 9**).

On average networked and organizational were ranked higher by healthcare professionals in comparison with patients views of the frequently visited source of POMI.

Human sources, printed media and broadcast media were ranked lower by health care professionals (**Table 10**).

To further test whether there are significant differences between health care professionals and patients Z-test was run for the comparison between “yes” proportions of physicians and patients. There were significant differences ($P=.000$) in the proportion for all the sources except for talking with physicians or physicians’ assistant ($P=.0048$), talking with other patients ($P=.0030$), talking with relatives, friends and acquaintances ($P=0.2327$), email from relatives/friends/acquaintances ($P=.0026$), books ($P=.0039$), TV/radio ($P=.0436$), newspaper/magazines ($P=.3360$) and films/movies ($P=.0002$) (**Table 10**). Comparison of the analysis for both the groups (physicians and patients) support hypothesis 2 for a majority of sources.

Hypothesis 3

The third hypothesis proposed that health care professional’s perception about the quality of POMI used by cancer patients will be different from the patients’ view of the same

Frequency test and descriptive analysis were run for the quality of information of all the POMI sources. On the whole, with the exception of organizational sources: educational program by HMO/hospital and national/local medical information services, all the other sources were ranked lower for the quality of information obtained by the healthcare professionals in comparison to the patients (**Table 11**).

To further test whether there are significant differences between health care professionals independent sample t-test and z-test were run to compare the population mean of the quality of information obtained from sources of POMI between two groups (Table 13).

Results indicated that there were 1) high significant differences in the views of two groups about the quality of information obtained from talking with a support group, talking with other patients, email/chat room with other patients, email from relatives/friends/acquaintances, narratives (written stories by other patients), books, Internet/medical websites, TV/radio, News paper magazines and films/movies, 2) low significant differences in differences in the views or two groups about the quality of information obtained from talking with nurse/other health professionals, email/chat room with a support group, telephone/helpline and audio/video tapes and 3) no significant differences for the other sources (**Table 12**). **Table 13** lists in detail the views about the quality of information from sources of POMI for both the groups. Comparison of the analysis for both the groups support hypothesis 3 for a majority of sources.

Hypothesis 4

The fourth hypothesis proposed that health care professional's perception of the expected quality of information from future sources of POMI will be different from cancer patients' perception of the same.

Frequency test and descriptive analysis were run for the quality of information of all the POMI sources. All the sources were ranked lower for the quality of information obtained by the healthcare professionals in comparison to the patients (**Table 14**).

To further test whether there are significant differences between health care professionals independent sample t-test or z-test were run to compare the population mean of the quality of information obtained from sources of POMI between two groups (Table 13). Results indicated that there were 1) significant differences in the views of two groups about the quality of information obtained from talking with other patients, talking with

relatives/friends/acquaintances, email/chat room with other patients, email from relatives/friends/acquaintances, narratives (written stories by other patients), Internet/medical websites, Newspaper/magazines, films/movies, talking with nurse/other health professionals, email/chat room with a support group, telephone/helpline and TV/radio (**Table 15**). **Table 16** lists in detail the views about the quality of information from sources of POMI for both the groups. Comparison of the analysis for both the groups support hypothesis 4 for a majority of sources.

Hypothesis 5

The fifth hypothesis proposed that health care professional's perception about the predictors of information seeking behavior of cancer patients will be different from patients' perception of the same.

Analysis from Chen Wang's study indicates that 1) age, race, education and computer ownership have some predicting power for the use of sources and 2) other demographic factors do not influence the information seeking behavior of the patient (**Table 17**).

There is a significant difference in the health care professionals' views of the predictors of the information seeking behavior of the patients. Analysis from this study indicates that 1) majority of healthcare professionals feel that age, race, education, working status, household income and computer access impact the information seeking behavior of the patients, 2) slightly more than half of healthcare professionals feel that general health condition and gender impact the information seeking behavior of the patients and 3) less than half of the healthcare professional feel that insurance coverage impact the information seeking behavior of the patients (**Table 18**).

Table 4: Demographics of Medical Information Sources Survey Responders

Characteristics	Demographics Questions	N	Analysis (%)
Position	Oncologists	42	63.6%
	Oncology Nurse	17	25.7%
	Research Nurse	2	3.0%
	Research Administrator	2	3.0%
	Others	3	4.5%
Gender	Male	34	51.5%
	Female	32	48.4%
Age	21-30	2	3.1%
	31-40	21	33.3%
	41-50	26	41.2%
	51-60	12	19.0%
	61-70	1	1.5%
	71-80	1	1.5%
Years of Practice	1-5	7	11.8%
	6-10	12	20.3%
	11-15	14	23.7%
	16-20	12	20.3%
	21-25	8	13.5%
	26-30	3	5.0%
	>30	3	5.0%
Use of Internet	No	2	3.0%
	Yes	61	92.4%
Type of Cancer	Breast	10	15.1%
	Gastro Intestinal	11	16.6%
	Head & Neck	3	4.5%
	Haematological Malignancies	5	7.5%
	Lung	19	28.7%
	Urinary/Genitourinary	4	6.0%
	Others	14	21.2%
Geographic Location	Urban	20	30.3%
	Counties outside metro statistical area	6	9.0%
	Metropolitan area	37	56.0%
	Rural health professional shortage area	3	4.5%
Practice Setting	Solo	6	9.0%
	Free-standing clinic	3	4.5%
	Hospital	14	21.2%
	Group office	8	12.1%
	Medical School	33	50.0%
	Other	2	3.0%

Table 5: Demographic Differences between Health Care Professionals

Demographics	Differences among health care professionals
	P value (N=66)
Years of Practice	0.089
Geographic location of practice	0.810
Type of practice setting	0.000
Use of Internet	0.148
Age	0.014
Type of Cancer treated frequently	0.235
Gender	0.000

Table 6: Demographic Differences between types of Cancer Treated

Demographics	Differences among type of cancer treated
	P value (N=66)
Years of Practice	0.929
Geographic location of practice	0.858
Type of practice setting	0.670
Use of Internet	0.547
Age	0.879
Position	0.235
Gender	0.047

Table 7: Ranking Comparison for Past POMI Sources (Physician vs. Patient)

Source-Past	Physician			Patient		
	Ranking	N	Yes % (N=66)	Ranking	N	Yes % (N=257)
Talking with physician or physicians assistant	1	65	98.5%	1	252	98.1%
Talking with nurse/other health professionals	2	64	97.0%	2	215	83.7%
Talking with other patients	3	63	95.5%	4	133	51.8%
Talking with relatives/friends/acquaintances	4	62	93.9%	3	169	65.8%
Internet/medical websites	5	62	93.9%	7	101	39.3%
Medical leaflets/pamphlets	6	61	92.4%	5	129	50.2%
Talking with a support group	7	59	89.4%	12	42	16.3%
Newspaper/magazines	8	58	89.2%	8	97	37.7%
TV/radio	9	56	84.8%	9	69	26.8%
National/local medical information services	10	54	83.1%	14	38	14.8%
Books	11	53	80.3%	6	128	49.8%
Email from relatives/friends/acquaintances	12	45	69.2%	13	39	15.2%
Email/chat room with a support group	13	45	68.2%	21	13	5.1%
Narratives(written stories by other patients)	14	42	63.6%	11	49	19.1%
Educational program by HMO/hospital	15	39	60.0%	16	24	9.3%
Telephone/helpline	16	38	58.5%	19	18	7.0%
Email/chat room with other patients	17	38	57.6%	22	9	3.5%
Audio/video tapes	18	34	51.5%	17	24	9.3%
Medical Journals	19	33	50.0%	10	54	21.0%
Films/movies	20	32	49.2%	15	25	9.7%
Email from physician or physician's assistant	21	24	36.4%	18	20	7.8%
Email from nurse/other health professionals	22	24	36.4%	20	16	6.2%

Table 8: Ranking comparison by Different Source Type (Physician vs. Patient)

Source-Past		Physician	Patient	Proportion significance (P Value)
Human Sources	Frequency Utilization	89.7%	55.8%	
Talking with physician or physicians assistant		1	1	.4090
Talking with nurse/other health professionals		2	2	.0025
Talking with a support group		7	12	.0000
Talking with other patients		3	4	.0000
Talking with relatives/friends/acquaintances		4	3	.0000
Narratives(written stories by other patients)		14	11	.0000
Printed Media	Frequency Utilization	78.0%	39.7%	
Medical leaflets/pamphlets		6	5	.0000
Books		11	6	.0000
Medical Journals		19	10	.0000
Newspaper/magazines		8	8	.0000
Networked Sources	Frequency Utilization	60.0%	12.0%	
Email from physician or physician's assistant		21	18	.0000
Email from nurse/other health professionals		22	20	.0000
Email/chat room with a support group		13	21	.0000
Email/chat room with other patients		17	22	.0000
Email from relatives/friends/acquaintances		12	13	.0000
Internet/medical websites		6	7	.0000
Telephone/helpline		13	20	.0000
Broadcast Media	Frequency Utilization	67.0%	18.25	
TV/radio		9	9	.0000
Films/movies		20	15	.0000
Organizational Sources	Frequency Utilization	71.6%	12.1%	
Educational program by HMO/hospital		15	16	.0000
National/local medical information services		10	14	.0000
Other Sources	Frequency Utilization	51.5%	9.3%	
Audio/video tapes		18	17	.0000

Table 9: Ranking Comparison for Future POMI Sources (Physician vs. Patient)

Source-Future	Ranking	Physician		Ranking	Patient	
		N	Yes % (N=66)		N	Yes % (N=257)
Talking with physician or physicians assistant	1	64	97.0%	1	219	85.2%
Talking with nurse/other health professionals	2	61	92.4%	2	178	69.3%
National/local medical information services	3	58	89.2%	14	31	12.1%
Medical leaflets/pamphlets	4	57	86.4%	6	99	38.5%
Talking with a support group	5	52	78.8%	12	38	14.8%
Internet/medical websites	6	51	78.5%	7	87	33.9%
Educational program by HMO/hospital	7	43	66.2%	15	28	10.9%
Books	8	43	66.2%	5	105	40.9%
Talking with other patients	9	41	62.1%	4	111	43.2%
Medical Journals	10	39	59.1%	10	51	19.8%
Audio/video tapes	11	33	50.0%	17	16	6.2%
Email from physician or physician's assistant	12	31	47.0%	16	18	7.0%
Telephone/helpline	13	28	43.1%	20	12	4.7%
Talking with relatives/friends/acquaintances	14	28	42.4%	3	122	47.5%
Newspaper/magazines	15	27	41.5%	8	75	29.2%
Narratives(written stories by other patients)	16	27	40.9%	11	41	16.0%
Email from nurse/other health professionals	17	26	39.4%	19	14	5.4%
Email/chat room with a support group	18	24	36.4%	21	11	4.3%
TV/radio	19	21	31.8%	9	56	21.8%
Email from relatives/friends/acquaintances	20	17	26.2%	13	122	12.1%
Email/chat room with other patients	21	16	24.2%	22	6	2.3%
Films/movies	22	13	20.0%	18	15	5.8%

Table 10: Ranking Comparison for Future POMI Sources by Different Source Type (Physician vs. Patient)

Sources		Physician	Patient	Proportion Significance (P-value)
Human Sources	Frequency Utilization	69.0%	46.0%	
Talking with physician or physicians assistant		1	1	.0048
Talking with nurse/other health professionals		2	2	.0025
Talking with a support group		5	12	.0000
Talking with other patients		9	4	.0030
Talking with relatives/friends/acquaintances		14	3	.2327
Narratives(written stories by other patients)		16	11	.0000
Printed Media	Frequency Utilization	63.3%	32.1%	
Medical leaflets/pamphlets		4	6	.0000
Books		8	5	.0039
Medical Journals		10	10	.0000
Newspaper/magazines		15	8	.3360
Networked Sources	Frequency Utilization	42.1%	9.95%	
Email from physician or physician's assistant		12	16	.0000
Email from nurse/other health professionals		17	19	.0000
Email/chat room with a support group		18	21	.0000
Email/chat room with other patients		21	22	.0000
Email from relatives/friends/acquaintances		20	13	.0026
Internet/medical websites		6	7	.0000
Telephone/helpline		13	20	.0000
Broadcast Media	Frequency Utilization	25.9%	13.8%	
TV/radio		19	9	.0436
Films/movies		22	18	.0002
Organizational Sources	Frequency Utilization	77.7%	11.5%	
Educational program by HMO/hospital		7	15	.0000
National/local medical information services		3	14	.0000
Other Sources	Frequency Utilization	50.0%	6.2%	
Audio/video tapes		11	17	.0000

Table 11: Comparison of Quality of Information from POMI Sources (PAST)

Source	Physician	N=66	Patient	N=257
Human Sources	Quality Mean	N	Quality Mean	N
Talking with physician or physicians assistant	6.2	65	6.29	250
Talking with nurse/other health professionals	5.62	64	6.06	215
Talking with a support group	4.35	60	4.64	44
Talking with other patients	3.75	63	5.12	130
Talking with relatives/friends/acquaintances	2.68	63	4.87	166
Narratives(written stories by other patients)	3.8	44	5.1	48
Printed Media				
Medical leaflets/pamphlets	5.31	61	5.59	126
Books	4.79	53	5.56	126
Medical Journals	5.64	36	5.83	99
Newspaper/magazines	3.11	56	4.72	97
Networked Sources				
Email from physician or physician's assistant	5.24	25	5.68	19
Email from nurse/other health professionals	4.96	25	5.21	14
Email/chat room with a support group	3.42	45	4.85	13
Email/chat room with other patients	3.31	39	5.11	9
Email from relatives/friends/acquaintances	2.58	45	4.61	38
Internet/medical websites	4.2	60	5.68	99
Telephone/helpline	4	39	5.11	19
Broadcast Media				
TV/radio	2.93	54	4.44	68
Films/movies	2.51	35	5.08	26
Organizational Sources				
Educational program by HMO/hospital	5.35	40	5.23	26
National/local medical information services	5.45	53	5.39	36
Other Sources				
Audio/video tapes	4.36	36	5.31	26

Table 12: Quality Significance Test for Information from POMI Sources (PAST)

Source	P value
Talking with physician or physicians assistant	0.2709
Talking with nurse/other health professionals	0.0013
Talking with a support group	0.1685
Talking with other patients	0.0000
Talking with relatives/friends/acquaintances	0.0000
Email from physician or physician's assistant	0.3460
Email from nurse/other health professionals	0.6310
Email/chat room with a support group	0.0075
Email/chat room with other patients	0.0000
Email from relatives/friends/acquaintances	0.0000
Educational program by HMO/hospital	0.3707
National/local medical information services	0.4207
Medical leaflets/pamphlets	0.0571
Narratives(written stories by other patients)	0.0000
Books	0.0002
Medical Journals	0.2358
Internet/medical websites	0.0000
Telephone/helpline	0.0071
TV/radio	0.0000
Newspaper/magazines	0.0000
Audio/video tapes	0.0096
Films/movies	0.0000

Table 13: Detailed Description of Quality of Information from POMI Sources (PAST)

Sources	N	Physician		N	Patient	
Talking with Physician or Physician's Assistant		Very Poor = 1	0.0%		Very Poor = 1	0.0%
		Poor = 2	1.5%		Poor = 2	0.0%
		Below Average = 3	1.5%		Below Average = 3	1.2%
	65	Average = 4	3.1%	250	Average = 4	4.8%
		Good = 5	15.4%		Good = 5	12.4%
		Very Good = 6	26.2%		Very Good = 6	26.8%
		Excellent = 7	52.3%		Excellent = 7	54.8%
		Mean	6.2		Mean	6.29
Talking with Nurse or Other Health Professionals		Very Poor = 1	0.0%		Very Poor = 1	0.0%
		Poor = 2	0.0%		Poor = 2	0.0%
		Below Average = 3	3.1%		Below Average = 3	0.5%
	64	Average = 4	12.5%	215	Average = 4	6.5%
		Good = 5	20.3%		Good = 5	20.0%
		Very Good = 6	46.9%		Very Good = 6	33.0%
		Excellent = 7	17.2%		Excellent = 7	40.0%
		Mean	5.62		Mean	6.06
Talking with a Support Group		Very Poor = 1	0.0%		Very Poor = 1	6.8%
		Poor = 2	6.7%		Poor = 2	4.5%
		Below Average = 3	11.7%		Below Average = 3	9.1%
	60	Average = 4	38.3%	44	Average = 4	29.5%
		Good = 5	30.0%		Good = 5	20.5%
		Very Good = 6	10.0%		Very Good = 6	6.8%
		Excellent = 7	3.3%		Excellent = 7	22.7%
		Mean	4.35		Mean	4.64

Table 13 Continued

Sources	N	Physician		N	Patient	
Talking with Other Patients		Very Poor = 1	4.8%		Very Poor = 1	0.0%
		Poor = 2	7.9%		Poor = 2	3.8%
		Below Average = 3	27.0%		Below Average = 3	5.4%
	63	Average = 4	38.1%	130	Average = 4	25.4%
		Good = 5	14.3%		Good = 5	25.4%
		Very Good = 6	6.3%		Very Good = 6	20.0%
		Excellent = 7	1.6%		Excellent = 7	20.0%
		Mean	3.75		Mean	5.12
Talking with Relatives, Friends, and Acquaintances		Very Poor = 1	19.0%		Very Poor = 1	3.0%
		Poor = 2	23.8%		Poor = 2	7.2%
		Below Average = 3	34.9%		Below Average = 3	9.0%
	63	Average = 4	17.5%	166	Average = 4	19.3%
		Good = 5	1.6%		Good = 5	25.3%
		Very Good = 6	3.2%		Very Good = 6	14.5%
		Excellent = 7	0.0%		Excellent = 7	21.7%
		Mean	2.68		Mean	4.87
Email from Physician or Physician's Assistant		Very Poor = 1	0.0%		Very Poor = 1	5.3%
		Poor = 2	8.0%		Poor = 2	2.8%
		Below Average = 3	4.0%		Below Average = 3	5.3%
	25	Average = 4	16.0%	19	Average = 4	5.3%
		Good = 5	20.0%		Good = 5	15.8%
		Very Good = 6	32.0%		Very Good = 6	31.6%
		Excellent = 7	20.0%		Excellent = 7	36.8%
		Mean	5.24		Mean	5.68

Table 13 Continued

Sources	N	Physician		N	Patient	
Email from Nurse or Other Health Professionals		Very Poor = 1	0.0%		Very Poor = 1	7.1%
		Poor = 2	8.0%		Poor = 2	0.0%
		Below Average = 3	8.0%		Below Average = 3	7.1%
	25	Average = 4	24.0%	14	Average = 4	14.3%
		Good = 5	8.0%		Good = 5	21.4%
		Very Good = 6	44.0%		Very Good = 6	21.4%
		Excellent = 7	8.0%		Excellent = 7	28.6%
		Mean	4.96		Mean	5.21
Email or Chat-room with a Support Group		Very Poor = 1	6.7%		Very Poor = 1	7.7%
		Poor = 2	13.3%		Poor = 2	7.7%
		Below Average = 3	24.4%		Below Average = 3	7.7%
	45	Average = 4	42.2%	13	Average = 4	23.1%
		Good = 5	13.3%		Good = 5	7.7%
		Very Good = 6	0.0%		Very Good = 6	15.4%
		Excellent = 7	0.0%		Excellent = 7	30.8%
		Mean	3.42		Mean	4.85
Email or Chat-room with Other Patients		Very Poor = 1	2.6%		Very Poor = 1	11.1%
		Poor = 2	15.4%		Poor = 2	0.0%
		Below Average = 3	41.0%		Below Average = 3	11.1%
		Average = 4	33.3%	9	Average = 4	11.1%
	39	Good = 5	5.1%		Good = 5	11.1%
		Very Good = 6	2.6%		Very Good = 6	22.2%
		Excellent = 7	0.0%		Excellent = 7	33.3%
		Mean	3.31		Mean	5.11

Table 13 Continued

Sources	N	Physician		N	Patient	
Email from Relatives, Friends, and Acquaintances		Very Poor = 1	22.2%		Very Poor = 1	5.3%
		Poor = 2	20.0%		Poor = 2	13.2%
		Below Average = 3	40.0%		Below Average = 3	7.9%
	45	Average = 4	15.6%	38	Average = 4	15.8%
		Good = 5	0.0%		Good = 5	23.7%
		Very Good = 6	2.2%		Very Good = 6	15.8%
		Excellent = 7	0.0%		Excellent = 7	18.4%
		Mean	2.58		Mean	4.61
Educational Programs by HMO or Hospital		Very Poor = 1	0.0%		Very Poor = 1	3.8%
		Poor = 2	0.0%		Poor = 2	0.0%
		Below Average = 3	7.5%		Below Average = 3	15.4%
	40	Average = 4	10.0%	26	Average = 4	7.7%
		Good = 5	35.0%		Good = 5	23.1%
		Very Good = 6	35.0%		Very Good = 6	23.1%
		Excellent = 7	12.5%		Excellent = 7	26.9%
		Mean	5.35		Mean	5.23
National/Local Medical Information Services		Very Poor = 1	0.0%		Very Poor = 1	2.8%
		Poor = 2	1.9%		Poor = 2	0.0%
		Below Average = 3	5.7%		Below Average = 3	8.3%
	53	Average = 4	11.3%	36	Average = 4	13.9%
		Good = 5	24.5%		Good = 5	22.2%
		Very Good = 6	39.6%		Very Good = 6	25.0%
		Excellent = 7	17.0%		Excellent = 7	27.8%
		Mean	5.45		Mean	5.39

Table 13 Continued

Sources	N	Physician		N	Patient	
Medical Leaflets or Pamphlets		Very Poor = 1	0.0%		Very Poor = 1	1.6%
		Poor = 2	0.0%		Poor = 2	0.0%
		Below Average = 3	3.3%		Below Average = 3	3.2%
	61	Average = 4	21.3%	126	Average = 4	11.9%
		Good = 5	32.8%		Good = 5	25.4%
		Very Good = 6	26.2%		Very Good = 6	32.5%
		Excellent = 7	16.4%		Excellent = 7	25.4%
		Mean	5.31		Mean	5.59
Narratives		Very Poor = 1	2.3%		Very Poor = 1	4.2%
		Poor = 2	6.8%		Poor = 2	2.1%
		Below Average = 3	40.9%		Below Average = 3	8.3%
	44	Average = 4	22.7%	48	Average = 4	18.8%
		Good = 5	18.2%		Good = 5	14.6%
		Very Good = 6	4.5%		Very Good = 6	35.4%
		Excellent = 7	4.5%		Excellent = 7	16.7%
		Mean	3.8		Mean	5.1
Books		Very Poor = 1	1.9%		Very Poor = 1	1.6%
		Poor = 2	0.0%		Poor = 2	3.2%
		Below Average = 3	7.5%		Below Average = 3	2.4%
	53	Average = 4	35.8%	126	Average = 4	11.1%
		Good = 5	26.4%		Good = 5	21.4%
		Very Good = 6	18.9%		Very Good = 6	33.3%
		Excellent = 7	9.4%		Excellent = 7	27.0%
		Mean	4.79		Mean	5.56

Table 13 Continued

Sources	N	Physician		N	Patient	
Medical Journals		Very Poor = 1	0.0%		Very Poor = 1	0.0%
		Poor = 2	2.8%		Poor = 2	0.0%
		Below Average = 3	2.8%		Below Average = 3	1.9%
	36	Average = 4	13.9%	99	Average = 4	13.0%
		Good = 5	19.4%		Good = 5	20.4%
		Very Good = 6	30.6%		Very Good = 6	29.6%
		Excellent = 7	30.6%		Excellent = 7	35.2%
		Mean	5.64		Mean	5.83
Internet or Medical Websites		Very Poor = 1	0.0%		Very Poor = 1	1.0%
		Poor = 2	11.7%		Poor = 2	0.0%
		Below Average = 3	18.3%		Below Average = 3	1.0%
	60	Average = 4	21.7%	99	Average = 4	13.1%
		Good = 5	36.7%		Good = 5	31.3%
		Very Good = 6	10.0%		Very Good = 6	20.2%
		Excellent = 7	1.7%		Excellent = 7	33.3%
		Mean	4.2		Mean	5.68
Telephone or Helpline		Very Poor = 1	2.6%		Very Poor = 1	5.3%
		Poor = 2	10.3%		Poor = 2	5.3%
		Below Average = 3	23.1%		Below Average = 3	5.3%
	39	Average = 4	30.8%	19	Average = 4	10.5%
		Good = 5	17.9%		Good = 5	31.6%
		Very Good = 6	12.8%		Very Good = 6	15.8%
		Excellent = 7	2.6%		Excellent = 7	26.3%
		Mean	4		Mean	5.11

Table 13 Continued

Sources	N	Physician		N	Patient	
		Very Poor = 1	14.8%		Very Poor = 1	4.4%
		Poor = 2	27.8%		Poor = 2	5.9%
		Below Average = 3	16.7%		Below Average = 3	14.7%
TV/Radio	54	Average = 4	31.5%	68	Average = 4	30.9%
		Good = 5	9.3%		Good = 5	19.1%
		Very Good = 6	0.0%		Very Good = 6	10.3%
		Excellent = 7	0.0%		Excellent = 7	14.7%
		Mean	2.93		Mean	4.44
		Very Poor = 1	7.1%		Very Poor = 1	4.1%
		Poor = 2	32.1%		Poor = 2	2.1%
		Below Average = 3	25.0%		Below Average = 3	10.3%
Newspapers/Magazines	56	Average = 4	23.2%	97	Average = 4	25.8%
		Good = 5	5.4%		Good = 5	27.8%
		Very Good = 6	5.4%		Very Good = 6	18.6%
		Excellent = 7	1.8%		Excellent = 7	11.3%
		Mean	3.11		Mean	4.72
		Very Poor = 1	0.0%		Very Poor = 1	3.8%
		Poor = 2	8.3%		Poor = 2	3.8%
		Below Average = 3	16.7%		Below Average = 3	3.8%
Audio/Video Tapes	36	Average = 4	30.6%	26	Average = 4	23.1%
		Good = 5	30.6%		Good = 5	11.5%
		Very Good = 6	2.8%		Very Good = 6	19.2%
		Excellent = 7	11.1%		Excellent = 7	34.6%
		Mean	4.36		Mean	5.31

Table 13 Continued

Sources	N	Physician		N	Patient	
		Very Poor = 1	25.7%		Very Poor = 1	3.8%
		Poor = 2	34.3%		Poor = 2	3.8%
		Below Average = 3	17.1%		Below Average = 3	11.5%
Films/Movies	35	Average = 4	14.3%	26	Average = 4	11.5%
		Good = 5	5.7%		Good = 5	23.1%
		Very Good = 6	2.9%		Very Good = 6	23.1%
		Excellent = 7	0.0%		Excellent = 7	23.1%
		Mean	2.51		Mean	5.08

Table 14: Comparison of Quality of Information from POMI Sources (FUTURE)

Future	Physician	N=66	Patient	N=257
Human Sources	Quality Mean	N	Quality Mean	N
Talking with physician or physicians assistant	6.42	64	6.45	220
Talking with nurse/other health professionals	5.85	61	6.21	182
Talking with a support group	4.89	54	5.05	38
Talking with other patients	4.36	42	5.23	111
Talking with relatives/friends/acquaintances	3.21	34	5.01	124
Narratives(written stories by other patients)	4.4	30	5.43	42
Printed Media				
Medical leaflets/pamphlets	5.67	58	5.98	101
Books	4.91	47	5.81	106
Medical Journals	5.9	40	5.92	53
Newspaper/magazines	3.62	29	4.85	79
Networked Sources				
Email from physician or physician's assistant	5.68	34	6.21	19
Email from nurse/other health professionals	5.52	29	6.17	12
Email/chat room with a support group	4.28	32	5.58	12
Email/chat room with other patients	3.9	20	6.67	6
Email from relatives/friends/acquaintances	3.52	21	4.81	32
Internet/medical websites	4.94	51	5.78	90
Telephone/helpline	4.29	31	5.64	11
Broadcast Media				
TV/radio	3.69	26	4.6	58
Films/movies	3.33	18	5.38	16
Organizational Sources				
Educational program by HMO/hospital	5.65	43	5.96	28
National/local medical information services	5.9	58	5.94	32
Other Sources				
Audio/video tapes	4.63	35	5.33	15

Table 15: Quality Significance Test for Information from POMI Sources (FUTURE)

Future-Quality	P value
Talking with physician or physicians assistant	.3974
Talking with nurse/other health professionals	.0049
Talking with a support group	.2946
Talking with other patients	.0000
Talking with relatives/friends/acquaintances	.0000
Email from physician or physician's assistant	.0352
Email from nurse/other health professionals	.1980
Email/chat room with a support group	.0062
Email/chat room with other patients	.0100
Email from relatives/friends/acquaintances	.0050
Educational program by HMO/hospital	.1401
National/local medical information services	.4286
Medical leaflets/pamphlets	.0268
Narratives(written stories by other patients)	.0002
Books	.0000
Medical Journals	.4681
Internet/medical websites	.0000
Telephone/helpline	.0064
TV/radio	.0180
Newspaper/magazines	.0001
Audio/video tapes	.0375
Films/movies	.0050

Table 16: Detailed Description of Quality of Information from POMI Sources (FUTURE)

Sources	N	Physician		N	Patient	
Talking with Physician or Physician's Assistant		Very Poor = 1	0.0%		Very Poor = 1	0.0%
		Poor = 2	0.0%		Poor = 2	0.0%
		Below Average = 3	0.0%		Below Average = 3	0.0%
	64	Average = 4	4.7%	220	Average = 4	3.2%
		Good = 5	7.8%		Good = 5	10.0%
		Very Good = 6	28.1%		Very Good = 6	25.0%
		Excellent = 7	59.4%		Excellent = 7	61.8%
		Mean	6.42		Mean	6.45
Talking with Nurse or Other Health Professionals		Very Poor = 1	0.0%		Very Poor = 1	0.0%
		Poor = 2	0.0%		Poor = 2	0.0%
		Below Average = 3	1.6%		Below Average = 3	0.5%
	61	Average = 4	6.6%	182	Average = 4	6.6%
		Good = 5	23.0%		Good = 5	12.1%
		Very Good = 6	42.6%		Very Good = 6	33.0%
		Excellent = 7	26.2%		Excellent = 7	47.8%
		Mean	5.85		Mean	6.21
Talking with a Support Group		Very Poor = 1	0.0%		Very Poor = 1	2.6%
		Poor = 2	0.0%		Poor = 2	2.6%
		Below Average = 3	9.3%		Below Average = 3	7.9%
	54	Average = 4	27.8%	38	Average = 4	26.3%
		Good = 5	35.2%		Good = 5	21.1%
		Very Good = 6	20.4%		Very Good = 6	13.2%
		Excellent = 7	7.4%		Excellent = 7	26.3%
		Mean	4.89		Mean	5.05

Table 16 Continued

Sources	N	Physician		N	Patient	
Talking with Other Patients		Very Poor = 1	0.0%		Very Poor = 1	0.0%
		Poor = 2	4.8%		Poor = 2	1.8%
		Below Average = 3	14.3%		Below Average = 3	3.6%
	42	Average = 4	38.1%	111	Average = 4	28.8%
		Good = 5	31.0%		Good = 5	23.4%
		Very Good = 6	7.1%		Very Good = 6	19.8%
		Excellent = 7	4.8%		Excellent = 7	22.5%
		Mean	4.36		Mean	5.23
Talking with Relatives, Friends, and Acquaintances		Very Poor = 1	8.8%		Very Poor = 1	0.0%
		Poor = 2	14.7%		Poor = 2	6.5%
		Below Average = 3	38.2%		Below Average = 3	9.7%
	34	Average = 4	26.5%	124	Average = 4	21.0%
		Good = 5	8.8%		Good = 5	27.4%
		Very Good = 6	2.9%		Very Good = 6	10.5%
		Excellent = 7	0.0%		Excellent = 7	25.0%
		Mean	3.21		Mean	5.01
Email from Physician or Physician's Assistant		Very Poor = 1	2.9%		Very Poor = 1	0.0%
		Poor = 2	2.9%		Poor = 2	0.0%
		Below Average = 3	0.0%		Below Average = 3	0.0%
	34	Average = 4	5.9%	19	Average = 4	0.0%
		Good = 5	17.6%		Good = 5	21.1%
		Very Good = 6	47.1%		Very Good = 6	36.8%
		Excellent = 7	23.5%		Excellent = 7	42.1%
		Mean	5.68		Mean	6.21

Table 16 Continued

Sources	N	Physician		N	Patient	
Email from Nurse or Other Health Professionals		Very Poor = 1	0.0%		Very Poor = 1	0.0%
		Poor = 2	0.0%		Poor = 2	0.0%
		Below Average = 3	10.3%		Below Average = 3	0.0%
	29	Average = 4	10.3%	12	Average = 4	8.3%
		Good = 5	17.2%		Good = 5	8.3%
		Very Good = 6	41.4%		Very Good = 6	41.7%
		Excellent = 7	20.7%		Excellent = 7	41.7%
		Mean	5.52		Mean	6.17
Email or Chat-room with a Support Group		Very Poor = 1	3.1%		Very Poor = 1	0.0%
		Poor = 2	3.1%		Poor = 2	8.3%
		Below Average = 3	18.8%		Below Average = 3	0.0%
	32	Average = 4	31.3%	12	Average = 4	16.7%
		Good = 5	28.1%		Good = 5	16.7%
		Very Good = 6	12.5%		Very Good = 6	16.7%
		Excellent = 7	3.1%		Excellent = 7	41.7%
		Mean	4.28		Mean	5.58
Email or Chat-room with Other Patients		Very Poor = 1	0.0%		Very Poor = 1	0.0%
		Poor = 2	5.0%		Poor = 2	0.0%
		Below Average = 3	25.0%		Below Average = 3	0.0%
		Average = 4	45.0%		Average = 4	0.0%
	20	Good = 5	25.0%	6	Good = 5	0.0%
		Very Good = 6	0.0%		Very Good = 6	33.3%
		Excellent = 7	0.0%		Excellent = 7	66.7%
		Mean	3.9		Mean	6.67

Table 16 Continued

Sources	N	Physician		N	Patient	
Email from Relatives, Friends, and Acquaintances		Very Poor = 1	4.8%		Very Poor = 1	3.1%
		Poor = 2	4.8%		Poor = 2	12.5%
		Below Average = 3	52.4%		Below Average = 3	3.1%
	21	Average = 4	23.8%	32	Average = 4	12.5%
		Good = 5	0.0%		Good = 5	34.4%
		Very Good = 6	14.3%		Very Good = 6	18.8%
		Excellent = 7	0.0%		Excellent = 7	15.6%
		Mean	3.52		Mean	4.81
Educational Programs by HMO or Hospital		Very Poor = 1	0.0%		Very Poor = 1	0.0%
		Poor = 2	0.0%		Poor = 2	0.0%
		Below Average = 3	2.3%		Below Average = 3	7.1%
	43	Average = 4	9.3%	28	Average = 4	7.1%
		Good = 5	30.2%		Good = 5	17.9%
		Very Good = 6	37.2%		Very Good = 6	17.9%
		Excellent = 7	20.9%		Excellent = 7	50.0%
		Mean	5.65		Mean	5.96
National/Local Medical Information Services		Very Poor = 1	0.0%		Very Poor = 1	0.0%
		Poor = 2	0.0%		Poor = 2	0.0%
		Below Average = 3	1.7%		Below Average = 3	0.0%
	58	Average = 4	5.2%	32	Average = 4	12.5%
		Good = 5	19.0%		Good = 5	21.9%
		Very Good = 6	50.0%		Very Good = 6	25.0%
		Excellent = 7	24.1%		Excellent = 7	40.6%
		Mean	5.9		Mean	5.94

Table 16 Continued

Sources	N	Physician		N	Patient	
Medical Leaflets or Pamphlets		Very Poor = 1	0.0%		Very Poor = 1	0.0%
		Poor = 2	0.0%		Poor = 2	0.0%
		Below Average = 3	1.7%		Below Average = 3	1.0%
	58	Average = 4	5.2%	101	Average = 4	9.9%
		Good = 5	39.7%		Good = 5	17.8%
		Very Good = 6	31.0%		Very Good = 6	32.7%
		Excellent = 7	22.4%		Excellent = 7	38.6%
		Mean	5.67		Mean	5.98
Narratives		Very Poor = 1	0.0%		Very Poor = 1	0.0%
		Poor = 2	3.3%		Poor = 2	2.4%
		Below Average = 3	20.0%		Below Average = 3	4.8%
	30	Average = 4	26.7%	42	Average = 4	14.3%
		Good = 5	40.0%		Good = 5	28.6%
		Very Good = 6	3.3%		Very Good = 6	26.2%
		Excellent = 7	6.7%		Excellent = 7	23.8%
		Mean	4.4		Mean	5.43
Books		Very Poor = 1	2.1%		Very Poor = 1	0.0%
		Poor = 2	0.0%		Poor = 2	0.9%
		Below Average = 3	2.1%		Below Average = 3	3.8%
	47	Average = 4	34.0%	106	Average = 4	4.7%
		Good = 5	34.0%		Good = 5	28.3%
		Very Good = 6	17.0%		Very Good = 6	28.3%
		Excellent = 7	10.6%		Excellent = 7	34.0%
		Mean	4.91		Mean	5.81

Table 16 Continued

Sources	N	Physician		N	Patient	
Medical Journals		Very Poor = 1	2.5%		Very Poor = 1	0.0%
		Poor = 2	0.0%		Poor = 2	0.0%
		Below Average = 3	0.0%		Below Average = 3	1.9%
	40	Average = 4	5.0%	53	Average = 4	9.4%
		Good = 5	17.5%		Good = 5	17.0%
		Very Good = 6	45.0%		Very Good = 6	37.7%
		Excellent = 7	30.0%		Excellent = 7	34.0%
		Mean	5.9		Mean	5.92
Internet or Medical Websites		Very Poor = 1	2.0%		Very Poor = 1	0.0%
		Poor = 2	2.0%		Poor = 2	0.0%
		Below Average = 3	3.9%		Below Average = 3	2.2%
	51	Average = 4	27.5%	90	Average = 4	11.1%
		Good = 5	29.4%		Good = 5	30.0%
		Very Good = 6	27.5%		Very Good = 6	20.0%
		Excellent = 7	7.8%		Excellent = 7	36.7%
		Mean	4.94		Mean	5.78
Telephone or Helpline		Very Poor = 1	6.5%		Very Poor = 1	0.0%
		Poor = 2	3.2%		Poor = 2	9.1%
		Below Average = 3	19.4%		Below Average = 3	0.0%
	31	Average = 4	19.4%	11	Average = 4	9.1%
		Good = 5	35.5%		Good = 5	18.2%
		Very Good = 6	9.7%		Very Good = 6	27.3%
		Excellent = 7	6.5%		Excellent = 7	36.4%
		Mean	4.29		Mean	5.64

Table 16 Continued

Sources	N	Physician		N	Patient	
TV/Radio		Very Poor = 1	7.7%		Very Poor = 1	5.2%
		Poor = 2	11.5%		Poor = 2	6.9%
		Below Average = 3	26.9%		Below Average = 3	8.6%
	26	Average = 4	30.8%	58	Average = 4	25.9%
		Good = 5	7.7%		Good = 5	24.1%
		Very Good = 6	11.5%		Very Good = 6	13.8%
		Excellent = 7	3.8%		Excellent = 7	15.5%
		Mean	3.69		Mean	4.6
Newspapers/Magazines		Very Poor = 1	10.3%		Very Poor = 1	2.5%
		Poor = 2	13.8%		Poor = 2	2.5%
		Below Average = 3	20.7%		Below Average = 3	8.9%
	29	Average = 4	27.6%	79	Average = 4	25.3%
		Good = 5	13.8%		Good = 5	27.8%
		Very Good = 6	13.8%		Very Good = 6	20.3%
		Excellent = 7	0.0%		Excellent = 7	12.7%
		Mean	3.62		Mean	4.85
Audio/Video Tapes		Very Poor = 1	5.7%		Very Poor = 1	0.0%
		Poor = 2	0.0%		Poor = 2	0.0%
		Below Average = 3	8.6%		Below Average = 3	6.7%
	35	Average = 4	34.3%	15	Average = 4	20.0%
		Good = 5	28.6%		Good = 5	20.0%
		Very Good = 6	8.6%		Very Good = 6	40.0%
		Excellent = 7	14.3%		Excellent = 7	13.3%
		Mean	4.63		Mean	5.33

Table 16 Continued

Sources	N	Physician		N	Patient	
Films/Movies		Very Poor = 1	16.7%		Very Poor = 1	0.0%
		Poor = 2	22.2%		Poor = 2	6.3%
		Below Average = 3	16.7%		Below Average = 3	0.0%
	18	Average = 4	16.7%	16	Average = 4	18.8%
		Good = 5	16.7%		Good = 5	18.8%
		Very Good = 6	5.6%		Very Good = 6	37.5%
		Excellent = 7	5.6%		Excellent = 7	18.8%
		Mean	3.33		Mean	5.38

Table 17: Predictors of Information Seeking Behavior (Patients’) (Source: Chen Wang)

Source	Stage	Gender	Age	Race	Education
Talking with physician or physicians assistant	0.303	0.249	0.225	0.047	0.069
Talking with nurse/other health professionals	0.623	0.474	0.079	0.071	0.186
Talking with a support group	0.173	0.526	0.183	0.002	0.582
Talking with other patients	0.989	0.107	0.045	0.482	0.022
Talking with relatives/friends/acquaintances	0.382	0.421	0.084	0.69	0.164
Email from physician or physician's assistant	0.799	0.327	0.379	0.40	0.275
Email from nurse/other health professionals	0.263	0.712	0.138	0.358	0.622
Email/chat room with a support group	0.920	0.538	0.130	0.079	0.585
Email/chat room with other patients	0.648	0.947	0.027	0.037	0.607
Email from relatives/friends/acquaintances	0.275	0.139	0.133	0.383	0.001
Educational program by HMO/hospital	0.98	0.645	0.266	0.005	0.014
National/local medical information services	0.006	0.044	0.646	0.082	0.090
Medical leaflets/pamphlets	0.395	0.002	0.015	0.135	0.038
Narratives(written stories by other patients)	0.864	0.136	0.023	0.212	0.072
Books	0.292	0.015	0.027	0.009	0.000
Medical Journals	0.272	0.010	0.700	0.012	0.003
Internet/medical websites	0.799	0.124	0.002	0.127	0.000
Telephone/helpline	0.901	0.694	0.896	0.000	0.342
TV/radio	0.261	0.196	0.784	0.036	0.848
Newspaper/magazines	0.027	0.213	0.497	0.031	0.059
Audio/video tapes	0.234	0.975	0.141	0.034	0.453
Films/movies	0.885	0.873	0.038	0.601	0.590

Table 17 Continued

Source	Working Status	Household Income	Insurance Coverage	Computer Access
Talking with physician or physicians assistant	0.500	0.070	0.797	0.173
Talking with nurse/other health professionals	0.438	0.094	0.593	0.028
Talking with a support group	0.333	0.421	0.631	0.394
Talking with other patients	0.060	0.177	0.942	0.001
Talking with relatives/friends/acquaintances	0.969	0.347	0.498	0.469
Email from physician or physician's assistant	0.412	0.101	0.574	0.097
Email from nurse/other health professionals	0.715	0.290	0.623	0.070
Email/chat room with a support group	0.829	0.764	0.665	0.112
Email/chat room with other patients	0.865	0.378	0.714	0.282
Email from relatives/friends/acquaintances	0.525	0.012	0.399	0.000
Educational program by HMO/hospital	0.153	0.195	0.213	0.032
National/local medical information services	0.268	0.010	0.553	0.018
Medical leaflets/pamphlets	0.299	0.676	0.981	0.011
Narratives(written stories by other patients)	0.265	0.138	0.105	0.165
Books	0.000	0.143	0.981	0.105
Medical Journals	0.098	0.423	0.863	0.031
Internet/medical websites	0.001	0.151	0.537	0.000
Telephone/helpline	0.666	0.853	0.130	0.317
TV/radio	0.100	0.002	0.291	0.064
Newspaper/magazines	0.715	0.327	0.121	0.432
Audio/video tapes	0.386	0.582	0.541	0.289
Films/movies	0.104	0.126	0.256	0.492

Table 18: Physicians Perspective of the Predictors of Information Seeking Behavior

Demographics	Yes (N=66)
Do you think stage is a predictor for patients' preference for sources of POMI?	60.9%
Do you think gender is a predictor for patients' preference for sources of POMI?	55.4%
Do you think age is a predictor for patients' preference for sources of POMI?	89.2%
Do you think race is a predictor for patients' preference for sources of POMI?	73.8%
Do you think education is a predictor for patients' preference for sources of POMI?	98.5%
Do you think working status is a predictor for patients' preference for sources of POMI?	80.0%
Do you think household income is a predictor for patients' preference for sources of POMI?	76.9%
Do you think insurance coverage is a predictor for patients' preference for sources of POMI?	36.9%
Do you think computer access is a predictor for patients' preference for sources of POMI?	95.4%

CHAPTER VI

DISCUSSION AND CONCLUSION

The objectives of this study were to identify the views of health care professionals on the patients' usage of various medical information sources, their evaluations of medical information quality, recommended medical information sources and difference in opinions with patient about the medical information sources. The results of the study contribute to understanding health care professionals' views of various medical information sources used by cancer patients. There were some interesting finds from these studies that have been discussed later in this chapter.

Several conclusions are supported by the data from this study. First, health care professionals reported current medical information sources (ranked by frequency) as human sources, printed media, organizational sources broadcast media, networked sources and other sources which is consistent only for "human sources" and "printed media" with Chen Wang's study and Informational Source Horizon Theory for general population (Savolainen et al., 2004). Even though both the groups prefer human sources and printed media as the most utilized sources, health care professionals were highly optimistic about the frequency of usage of human sources and printed media than compared to patients. Patients' frequency of utilization of human sources is 55.8% where as health care professionals expected it to be 89.7%. Similarly health care professionals expected 78.0% of the cancer patients to be utilizing print media to gather medical information, where as in reality only 39.7% of the patients reported using printed media. Since follow up questions were not asked in this study to identify the cause of difference in

perception of both the groups about the frequency of usage of medical information sources, future study conducted to investigate the cause can produce interesting results.

Second, for detailed source types it was not surprising that the top four most frequently used sources are all human sources. Consistent with previous studies, talking with physicians or physicians assistant and talking with nurse or other health professionals were reported as the top two medical information sources used by cancer patients in the past. The quality means of these two sources are 6.2 (6.22 by patients) and 5.62 (6.01 by patients), which were also among the top three among all the sources. These findings are consistent with previous studies that suggest that health professionals are the most trusted source for cancer information (Rutten etl al., 2004; Mills & Davidson, 2002; Kakai et al, 1999; O'Malley et al, 1999; Pennbridge et al, 1999; Cohn et al, 2003).

An interesting observation is that even though talking with relatives, friends and acquaintances has a mean quality of 2.68, health care professionals ranked it as the fourth most frequently used source by patients. The findings from my study support that for a majority number of medical information sources, healthcare professionals and patients have a different perception of the frequency of use by patients. Health care professionals always rated the mean quality of information from medical information sources lower than the patients for all the sources, especially for talking with relatives, friends and acquaintances (2.68 by physicians; 4.87 by patients) and, films and movies (2.51 by physicians; 5.08 by patients).

Another interesting finding is that even though health care professionals felt that they were the most frequently used source of cancer information, emails from health care professionals were ranked the lowest. This could be because health care professionals may not be finding sufficient time to correspond with the patients over email because of their busy schedule.

Third, health care professionals recommend medical information sources (ranked by frequency) as: organizational sources, human sources, printed media, other sources, networked sources and broadcast media which is totally inconsistent with the patients view of future sources of medical information from Chen Wang's study and Informational Source Horizon Theory for general population (Savolainen et al., 2004). Talking with physicians or physicians' assistant and talking with nurse or other health professionals were reported as the top two medical information sources. However, health care professionals rated only two human sources in the top four frequently used sources, where as patients rated all the top four frequently used sources as human sources, even though the mean quality of information expected from the other two human sources (talking with other patients and talking with friends/relatives/acquaintances) were ranked amongst the lowest by both the groups. An interesting observation is that health care professionals expect the mean quality of information from medical information sources to be lower than the patients expectations for all the sources, especially for films/movies (3.33 by physicians; 5.38 by patients) and email/chat room with other patients (3.9 by physicians; 6.67 by patients).

Health care professionals recommend that information gathered from other patients, relatives, friends and acquaintances either by talking or through email/chat room should be less frequently used and the quality of information is lower compared to other sources. However, patients rank these sources to be among the most frequently used for gathering medical information.

In general, health care professionals and patients view health professionals as the most the most trust source of medical information. However, there is a difference in opinion between both groups regarding majority the use and quality of other medical information sources.

Patients prefer to gather medical information sources from human sources, where as physicians recommend patients to make use of organizational sources and printed media. The results from this survey also indicate that health care professionals and patients have a different view of past and future medical information sources.

Fourth, health care professionals felt demographics of patients' influences patients' choice of medical information sources. More than 70% of the health care professionals felt that demographics including age, race, education, working status, household income and computer access influences patients' preference for medical information sources. These findings were consistent with Chen Wang's findings that age, education and computer access can be used as a predictor for medical information sources, but inconsistent for factors such as race, working status, gender, stage of cancer and household income of the patients. Therefore, the evidence from this study provides support that 1) certain patients' demographics can be used to determine the preference for the medical information sources (Galloway et al, 1997; Deridiarian, 1987; Bliss & Johnson, 1995; Bilodeau & Degner, 1996; Brandt, 1991) and 2) health care professionals and patients will have different perception about the predictors of the information seeking behavior.

This study has certain limitations. The sample size for this study was small (N=66) and thus may not be a good representation of the all health care professionals. Also, since majority of the participants in this study were oncologists (N=42), a bias in opinion could have been introduced.

Despite these shortcomings, this study is an indicator of health care professionals views the past and recommended medical information sources. However, further questions were not asked about why health care professionals recommended some sources over the other and what

they believe information can or cannot bring certain benefits such as reduction in anxiety. Future research needs to be done to investigate health care professionals view of the potential benefit of information on the cancer patients and why certain sources are recommend more frequently.

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 think patients have visited in the past and your recommendations to visit in the future, and the quality of the medical information that was obtained or expected from these sources.

Part A: Background Information

All information will be kept confidential.

(Please check one box per question.)

1	<p>What type of cancer do you treat?</p> <input type="checkbox"/> Bladder cancer <input type="checkbox"/> Breast cancer <input type="checkbox"/> Colon cancer <input type="checkbox"/> Endometrial cancer <input type="checkbox"/> Head and neck cancer <input type="checkbox"/> Leukemia	<input type="checkbox"/> Lung cancer <input type="checkbox"/> Melanoma <input type="checkbox"/> Non-Hodgkin's lymphoma <input type="checkbox"/> Ovarian cancer <input type="checkbox"/> Prostate cancer <input type="checkbox"/> Rectal cancer <input type="checkbox"/> <i>Other:</i> _____
2	<p>Do you think choice for the source of information varies with the gender of the patient?</p>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA
3	<p>Do you think choice for the source of information varies with the age of the patient?</p>	<input type="checkbox"/> Yes <input type="checkbox"/> No
4	<p>Do you think choice for the source of information varies with the educational qualification of the patient?</p>	<input type="checkbox"/> Yes <input type="checkbox"/> No
5	<p>Do you think choice for the source of information varies with the working status of the patient?</p>	<input type="checkbox"/> Yes <input type="checkbox"/> No
6	<p>Do you think choice for the source of information varies with the household income of the patient?</p>	<input type="checkbox"/> Yes <input type="checkbox"/> No

Part B: Medical Information Sources

All information will be kept confidential.

EXAMPLE Suppose you thought patients *FOUND* medical information both from books and TV/radio, and thought that the quality of information from Books was excellent but the information from TV/radio was poor, then you would check “Yes” for both, and circle “7” for the quality of information from Books and “1” for the quality of information from TV/radio;

Medical Information Sources		<u>Do</u> patients get Medical information from here? <input type="checkbox"/> Yes <input type="checkbox"/> No	If “Yes”, how good is the information quality?						
			Poor	→	Excellent				
16	Books	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
19	TV / radio	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7

Please check all that apply and circle the appropriate number.

Medical Information Sources		<u>Do</u> patients get Medical information from here? <input type="checkbox"/> Yes <input type="checkbox"/> No	If “Yes”, how good is the information quality?						
			Poor	→	Excellent				
1	Talking with physician or physician’s assistant	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
2	E-mail from physician or physician’s assistant	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
3	Talking with physician’s nurse / other health professionals in their office	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7

Please continue...

Medical Information Sources		<u>Section B1</u>								
		<u>Do</u> patients get Medical information from here?		If "Yes", how good is the information quality?						
				Poor	→					Excellent
4	E-mail from physician's nurse / other health professionals	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
5	Attending educational program by HMO / hospital	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
6	Talking with a support group	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
7	E-mails from a support group	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
8	Talking with other patients	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
9	E-mails from other patients	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
10	Narratives (written stories by other patients)	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
11	Talking with relatives / friends / acquaintances	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
12	E-mails from relatives / friends / acquaintances	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
13	National / local medical information services <i>(e.g. National Institute of Health / National Cancer Institute)</i>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
14	Medical leaflets / pamphlets	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
15	Medical journals / Medline / PubMed	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
16	Books	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
17	Internet medical web sites	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
18	Telephone / helpline	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
19	TV / radio	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
20	Newspapers / magazines	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
21	Audio / video tapes	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
22	Films / movies	<input type="checkbox"/> Yes	<input type="checkbox"/> 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 think patients have visited in the past and your recommendations to visit in the future, and the quality of the medical information that was obtained or expected from these sources.

Part A: Background Information	All information will be kept confidential.
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(Please check one box per question.)

1	<p align="center">What type of cancer do you treat?</p> <input type="checkbox"/> Bladder cancer <input type="checkbox"/> Breast cancer <input type="checkbox"/> Colon cancer <input type="checkbox"/> Endometrial cancer <input type="checkbox"/> Head and neck cancer <input type="checkbox"/> Leukemia	<input type="checkbox"/> Lung cancer <input type="checkbox"/> Melanoma <input type="checkbox"/> Non-Hodgkin's lymphoma <input type="checkbox"/> Ovarian cancer <input type="checkbox"/> Prostate cancer <input type="checkbox"/> Rectal cancer <input type="checkbox"/> <i>Other:</i> _____
2	<p>Do you think choice for the source of information varies with the gender of the patient?</p>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA
3	<p>Do you think choice for the source of information varies with the age of the patient?</p>	<input type="checkbox"/> Yes <input type="checkbox"/> No
4	<p>Do you think choice for the source of information varies with the educational qualification of the patient?</p>	<input type="checkbox"/> Yes <input type="checkbox"/> No
5	<p>Do you think choice for the source of information varies with the working status of the patient?</p>	<input type="checkbox"/> Yes <input type="checkbox"/> No
6	<p>Do you think choice for the source of information varies with the household income of the patient?</p>	<input type="checkbox"/> Yes <input type="checkbox"/> No

Part B: Medical Information Sources

All information will be kept confidential.

Section B1

EXAMPLE Suppose you thought patients **FOUND** medical information both from books and TV/radio, and thought that the quality of information from Books was excellent but the information from TV/radio was poor, then you would check “Yes” for both, and circle “7” for the quality of information from Books and “1” for the quality of information from TV/radio;

Medical Information Sources		<u>Do</u> patients get Medical information from here?	If “Yes”, how good is the information quality?						
			Poor	→					Excellent
16	Books	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
19	TV / radio	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7

Please check all that apply and circle the appropriate number.

Medical Information Sources		<u>Do</u> patients get Medical information from here?	If “Yes”, how good is the information quality?						
			Poor	→					Excellent
1	Talking with physician or physician’s assistant	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
2	E-mail from physician or physician’s assistant	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
3	Talking with physician’s nurse / other health professionals in their office	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7

Please continue...

Medical Information Sources		<i>Section B1</i>								
		<u>Do</u> patients get Medical information from here?		If "Yes", how good is the information quality?						
				Poor	→			Excellent		
4	E-mail from physician's nurse / other health professionals	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
5	Attending educational program by HMO / hospital	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
6	Talking with a support group	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
7	E-mails from a support group	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
8	Talking with other patients	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
9	E-mails from other patients	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
10	Narratives (written stories by other patients)	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
11	Talking with relatives / friends / acquaintances	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
12	E-mails from relatives / friends / acquaintances	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
13	National / local medical information services <i>(e.g. National Institute of Health / National Cancer Institute)</i>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
14	Medical leaflets / pamphlets	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
15	Medical journals / Medline / PubMed	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
16	Books	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
17	Internet medical web sites	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
18	Telephone / helpline	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
19	TV / radio	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
20	Newspapers / magazines	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
21	Audio / video tapes	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
22	Films / movies	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7

Section B2

EXAMPLE Suppose you **RECOMMEND** patients to search for **MORE** medical information from Books but not from TV/radio, and expect that the quality of the information from Books to be excellent, then you would check “Yes” for Books and circle “7” for the quality of information from Books, and check “No” for TV/radio. Your answer would be like:

Medical Information Sources		Do you recommend patients to get Medical information from here?	If “Yes”, how good you expect the information to be?								
			Poor	→	Excellent						
16	Books	<input type="checkbox"/> Yes <input type="checkbox"/> No			1	2	3	4	5	6	7
19	TV / radio	<input type="checkbox"/> Yes <input type="checkbox"/> No			1	2	3	4	5	6	7

Please check all that apply and circle the appropriate number.

Medical Information Sources		Do you recommend patients to get Medical information from here??	If “Yes”, how good you expect the information to be?								
			Poor	→	Excellent						
1	Talking with physician or physician’s assistant	<input type="checkbox"/> Yes <input type="checkbox"/> No			1	2	3	4	5	6	7
2	E-mail from physician or physician’s assistant	<input type="checkbox"/> Yes <input type="checkbox"/> No			1	2	3	4	5	6	7
3	Talking with physician’s nurse / other health professionals in their office	<input type="checkbox"/> Yes <input type="checkbox"/> No			1	2	3	4	5	6	7

Please continue...

Medical Information Sources		<i>Section B1</i>							
		<i>Do you recommend patients to get Medical information from here?</i>	<i>If "Yes", how good you expect the information to be?</i>						
			Poor	→	Excellent				
4	E-mail from physician's nurse / other health professionals	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
5	Attending educational program by HMO / hospital	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
6	Talking with a support group	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
7	E-mails from a support group	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
8	Talking with other patients	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
9	E-mails from other patients	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
10	Narratives (written stories by other patients)	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
11	Talking with relatives / friends / acquaintances	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
12	E-mails from relatives / friends / acquaintances	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
13	National / local medical information services <i>(e.g. National Institute of Health / National Cancer Institute)</i>	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
14	Medical leaflets / pamphlets	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
15	Medical journals / Medline / PubMed	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
16	Books	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
17	Internet medical web sites	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
18	Telephone / helpline	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
19	TV / radio	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
20	Newspapers / magazines	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
21	Audio / video tapes	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7
22	Films / movies	<input type="checkbox"/> Yes <input type="checkbox"/> No	1	2	3	4	5	6	7

APPENDIX C: QUESTIONNAIRE VERSION 3

Siddharth Rai, 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,

We are doing a study to investigate what oncologists, research nurses, and other care providers in oncology believe are sources of medical information for cancer patients and what they feel about the quality of such information. We also wish to investigate where care providers recommend cancer patients to go in the future for more information and what providers expect the quality of information to be from those sources.

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 reviewed and received approval from the Institutional Review Board at Vanderbilt University. For questions concerning this study or survey, please contact Siddharth Rai 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.

Siddharth Rai
Management of Technology Program
Vanderbilt University

Medical Information Sources Inquiry for Cancer Patients

Instructions

Thanks for taking this survey. The objective of this survey is to investigate the medical information sources that you believe your patients have visited in the past and may visit in the future. Additional interest is your estimation of the quality of such medical information.

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

In this part, we will investigate 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 patients have visited in past;

Section B2 asks about the medical information sources you recommend patients to 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 per question.)

1	<p>What type of cancer do you treat most frequently?</p> <p><input type="checkbox"/> Bladder cancer</p> <p><input type="checkbox"/> Breast cancer</p> <p><input type="checkbox"/> Colon cancer</p> <p><input type="checkbox"/> Endometrial cancer</p> <p><input type="checkbox"/> Head and neck cancer</p> <p><input type="checkbox"/> Leukemia</p>	<p><input type="checkbox"/> Lung cancer</p> <p><input type="checkbox"/> Melanoma</p> <p><input type="checkbox"/> Non-Hodgkin's lymphoma</p> <p><input type="checkbox"/> Ovarian cancer</p> <p><input type="checkbox"/> Prostate cancer</p> <p><input type="checkbox"/> Rectal cancer</p> <p><input type="checkbox"/> <i>Other:</i> _____</p>
2	<p>Do you believe choice for the source of information varies with the gender of the patient?</p>	<p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> NA</p>
3	<p>Do you believe choice for the source of information varies with the race of the patient?</p>	<p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p>
4	<p>Do you believe choice for the source of information varies with the educational qualification of the patient?</p>	<p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p>
5	<p>Do you believe choice for the source of information varies with the working status of the patient?</p>	<p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p>
6	<p>Do you believe choice for the source of information varies with the household income of the patient?</p>	<p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p>

Medical Information Sources All information will be kept confidential.

EXAMPLE Suppose you believe patients **FOUND** medical information both from books and TV/radio, and believe that the quality of information from Books was excellent but the information from TV/radio was poor, then you would check “Yes” for both, and circle “7” for the quality of information from Books and “1” for the quality of information from TV/radio; Suppose you **RECOMMEND** patients to search for **MORE** medical information from Books but not from TV/radio, and expect that the quality of the information from Books to be excellent, then you would check “Yes” for Books and circle “7” for the quality of information from Books, and check “No” for TV/radio. Your answer would be like:

Medical Information Sources		Section B1					Section B2												
		Do patients get Medical information from here?		If “Yes”, how good is the information quality?					Do you recommend patients to get Medical information from here?		If “Yes”, how good do you expect the information to be?								
				Very Poor → Excellent							Very Poor → Excellent								
16	Books	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
19	TV / radio	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7

Please check all that apply and circle the appropriate number

Medical Information Sources		Section B1					Section B2												
		Do patients get Medical information from here?		If “Yes”, how good do you expect the information to be?					Do you recommend patients to get Medical information from here?		If “Yes”, how good do you expect the information to be?								
				Very Poor → Excellent							Very Poor → Excellent								
1	Talking with physician or physician’s assistant	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
2	E-mail from physician or physician’s assistant	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
3	Talking with physician’s nurse / other health professionals in their office	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7

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

Medical Information Sources		<u>Section B1</u>					<u>Section B2</u>												
		<u>Do</u> patients get Medical information from here?		If "Yes", how good is the information quality?					<u>Do</u> you recommend patients to Medical information from here?		If "Yes", how good do you expect the information to be?								
				Very Poor → Excellent							Very Poor → Excellent								
4	E-mail from physician's nurse / other health professionals	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
5	Attending educational program by HMO / hospital	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
6	Talking with a support group	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
7	E-mails from a support group	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
8	Talking with other patients	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
9	E-mails from other patients	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
10	Narratives (written stories by other patients)	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
11	Talking with relatives / friends / acquaintances	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
12	E-mails from relatives / friends / acquaintances	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
13	National / local medical information services <i>(e.g. National Institute of Health / National Cancer Institute)</i>	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
14	Medical leaflets / pamphlets	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
15	Medical journals / Medline / PubMed	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
16	Books	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
17	Internet medical web sites	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
18	Telephone / helpline	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
19	TV / radio	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
20	Newspapers / magazines	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
21	Audio / video tapes	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7
22	Films / movies	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7	<input type="checkbox"/> Yes	<input type="checkbox"/> No	1	2	3	4	5	6	7

APPENDIX D: FINAL QUESTIONNAIRE

Siddharth Rai, 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,

We are doing a study to investigate what oncologists, research nurses, and other care providers in oncology believe are sources of medical information for cancer patients and what they feel about the quality of such information. We also wish to investigate where care providers recommend cancer patients to go in the future for more information and what providers expect the quality of information to be from those sources.

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 reviewed and received approval from the Institutional Review Board at Vanderbilt University. For questions concerning this study or survey, please contact Siddharth Rai 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.

Siddharth Rai
Management of Technology Program
Vanderbilt University

Medical Information Sources for Patients

Instructions

Thanks for taking this survey. The objective of this survey is to investigate the medical information sources that you believe your patients have visited in the past and may visit in the future. Additional interest is your estimation of the quality of such medical information.

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 asks about the medical information sources, including those your patients have visited in the past and may visit in the future.

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

Part C

In this part, we ask four opinion questions about different medical situations and how you view each.

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	What is your position: <input type="checkbox"/> oncologist <input type="checkbox"/> oncology nurse <input type="checkbox"/> research nurse <input type="checkbox"/> data manager <input type="checkbox"/> research administrator <input type="checkbox"/> other																											
2	What is your gender? <input type="checkbox"/> Male <input type="checkbox"/> Female																											
3	What is your age (in years)? _____																											
4	How many years have you been practicing? _____																											
5	Do you use Internet to gather medical information? <input type="checkbox"/> Yes <input type="checkbox"/> No																											
6	What type of cancer do you treat most frequently? <input type="checkbox"/> Bladder <input type="checkbox"/> Endometrial <input type="checkbox"/> Ovarian <input type="checkbox"/> Brain <input type="checkbox"/> Head/Neck <input type="checkbox"/> Prostate <input type="checkbox"/> Breast <input type="checkbox"/> Leukemia <input type="checkbox"/> Rectal <input type="checkbox"/> Colon <input type="checkbox"/> Lung <input type="checkbox"/> Non-Hodgkin's lymphoma <input type="checkbox"/> Melanoma <input type="checkbox"/> Other: _____																											
7	What would best describe the geographic location of your practice setting? <input type="checkbox"/> Urban area <input type="checkbox"/> Counties outside of a metropolitan statistical area <input type="checkbox"/> Metropolitan area <input type="checkbox"/> Rural health professional shortage area <input type="checkbox"/> Urban underserved area																											
8	What would best describe your practice setting? <input type="checkbox"/> Solo practitioner's office <input type="checkbox"/> HMO <input type="checkbox"/> Free- standing clinic <input type="checkbox"/> Hospital <input type="checkbox"/> Group office <input type="checkbox"/> Nursing Home/ Extended Care <input type="checkbox"/> Medical School <input type="checkbox"/> Other :																											
9	In your practice, do you believe that where patients obtain medical information varies by the following <i>patient characteristics</i>: <table style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 70%;">a. Gender</td> <td style="width: 15%;"><input type="checkbox"/> Yes</td> <td style="width: 15%;"><input type="checkbox"/> No</td> </tr> <tr> <td>b. Age</td> <td><input type="checkbox"/> Yes</td> <td><input type="checkbox"/> No</td> </tr> <tr> <td>c. Race</td> <td><input type="checkbox"/> Yes</td> <td><input type="checkbox"/> No</td> </tr> <tr> <td>d. Educational level (years of schooling)</td> <td><input type="checkbox"/> Yes</td> <td><input type="checkbox"/> No</td> </tr> <tr> <td colspan="3" style="border-top: 1px dashed black;">e. Working status / Occupation</td> </tr> <tr> <td>f. Household income</td> <td><input type="checkbox"/> Yes</td> <td><input type="checkbox"/> No</td> </tr> <tr> <td>g. Computer Access/Use</td> <td><input type="checkbox"/> Yes</td> <td><input type="checkbox"/> No</td> </tr> <tr> <td>h. Insurance Coverage</td> <td><input type="checkbox"/> Yes</td> <td><input type="checkbox"/> No</td> </tr> <tr> <td>i. General Health Condition</td> <td><input type="checkbox"/> Yes</td> <td><input type="checkbox"/> No</td> </tr> </table>	a. Gender	<input type="checkbox"/> Yes	<input type="checkbox"/> No	b. Age	<input type="checkbox"/> Yes	<input type="checkbox"/> No	c. Race	<input type="checkbox"/> Yes	<input type="checkbox"/> No	d. Educational level (years of schooling)	<input type="checkbox"/> Yes	<input type="checkbox"/> No	e. Working status / Occupation			f. Household income	<input type="checkbox"/> Yes	<input type="checkbox"/> No	g. Computer Access/Use	<input type="checkbox"/> Yes	<input type="checkbox"/> No	h. Insurance Coverage	<input type="checkbox"/> Yes	<input type="checkbox"/> No	i. General Health Condition	<input type="checkbox"/> Yes	<input type="checkbox"/> No
a. Gender	<input type="checkbox"/> Yes	<input type="checkbox"/> No																										
b. Age	<input type="checkbox"/> Yes	<input type="checkbox"/> No																										
c. Race	<input type="checkbox"/> Yes	<input type="checkbox"/> No																										
d. Educational level (years of schooling)	<input type="checkbox"/> Yes	<input type="checkbox"/> No																										
e. Working status / Occupation																												
f. Household income	<input type="checkbox"/> Yes	<input type="checkbox"/> No																										
g. Computer Access/Use	<input type="checkbox"/> Yes	<input type="checkbox"/> No																										
h. Insurance Coverage	<input type="checkbox"/> Yes	<input type="checkbox"/> No																										
i. General Health Condition	<input type="checkbox"/> Yes	<input type="checkbox"/> No																										
10	(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) <i>not at all important [1...2...3...4...5...6...7]critical to the choice</i>																											
11	(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) <i>not at all important [1...2...3...4...5...6...7]critical to the choice</i>																											

Part B: Medical Information Sources

All information will be kept confidential.

Section B

There are a number of sources of medical information. For example, a patient could have heard something on TV or 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. **Has** your typical patient 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 recommend the use of this medical source for information in the **future**?
4. What is your opinion of the expected quality of the information gathered from this source in the **future**?

EXAMPLE 1. Suppose you believe your typical patient has **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** recommend the use of *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 believe your typical patient has **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** recommend 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	
		<u>Do</u> patients get Medical information from	If "Yes", how good was the information quality? Very Poor → Excellent	<u>Will</u> you recommend medical information from	If "Yes", how good do you expect the information to be? Very Poor → Excellent
1	Books	<input checked="" type="checkbox"/> Yes	1...2...3...4...5...6...7	<input checked="" type="checkbox"/> Yes	1...2...3...4...5...6...7
2	TV/radio	<input checked="" type="checkbox"/> Yes	1...2...3...4...5...6...7	<input type="checkbox"/> 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**

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

Part C: Medical Scenarios

All information will be kept confidential.

In this section, there are a number of different scenarios. Please read each scenario and then circle the value that most closely fits **your** likelihood of making the choice. Use the following likelihood scale:

Likelihood Scale

- 1 Extremely Unlikely
- 2 Very Unlikely
- 3 Unlikely
- 4 Indifferent
- 5 Likely
- 6 Very Likely
- 7 Extremely Likely

For example, if you are indifferent to the choice in the scenario you would circle 4. If, on the other hand it is extremely likely that you chose the option, you would circle 7.

Scenario 1: Assume you wear glasses, but they are bothering you and are considering LASIK (Laser in Situ Keratomileusis) surgery. Searching the Internet using Google, you discover 332,000 “hits” on side effects and 31,500 “hits” on advantages. Searching Medline (a medical database containing journal articles physician use), you discover 13 articles on side effects and 637 articles on advantages of LASIK. **How likely are you to have LASIK surgery?**

Extremely Unlikely [1...2...3...4...5...6...7] Extremely Likely

Scenario 2: You have gone to your 60-year-old physician, who you have gone to all your life, for chronic back pain. She has suggested that you have lower back surgery. When searching the Internet for more information, you discover that surgery is not often done for low back pain because, in most cases, the cause of the pain cannot be helped by surgery (source: webMD.com).

How likely are you to follow the surgery recommendation?

Extremely Unlikely [1...2...3...4...5...6...7] Extremely Likely

Scenario 3: You notice a strange growth on your arm. You are not too concerned, but you spend half a day looking it up in the medical library. Everything you read says there is nothing to be concerned about. However, when walking to class, a fellow student sees it and remarks that they had something just like it and that it was malignant.

How likely are you to make a special appointment with your doctor about the growth?

Extremely Unlikely [1...2...3...4...5...6...7] Extremely Likely

Scenario 4: You have been diagnosed with Irritable Bowel Syndrome. Your primary care physician has informed you that two well known gastroenterologists have recently started practice in a local hospital, Dr. Zeta and Dr. Phi. When visiting Dr. Zeta’s office you are given a waiver to sign informing you that Dr. Zeta has no malpractice insurance and that you promise not to sue for any reason. Upon calling, you discover that Dr. Phi has insurance and does not require a waiver.

How likely are you to use Dr. Zeta’s services?

Extremely Unlikely [1...2...3...4...5...6...7] Extremely Likely

APPENDIX E: PROPOSAL SUBMITTED TO IRB

Principal Investigator: Siddharth Rai
 Study Title: Medical information sources for cancer patients- Oncologists perspective
 Institution/Hospital: Vanderbilt Ingram Cancer Center and Conference

Version Date: 04/08/04

Vanderbilt University Institutional Review Board Request for Exemption

1. Principal Investigator Information

First Name: Siddharth		Middle Initial:	Last Name: Rai	
Degree(s): <input type="checkbox"/> Ed.D. <input type="checkbox"/> J.D. <input type="checkbox"/> M.D. <input type="checkbox"/> Ph.D. <input type="checkbox"/> R.N. <input checked="" type="checkbox"/> Other, specify: M.S.				
Job Title: Graduate Student			Affiliation: <input checked="" type="checkbox"/> VU <input type="checkbox"/> Stallworth <input type="checkbox"/> VA-TN Valley HS <input type="checkbox"/> Other, specify:	
Department/Division: Management of Technology			School/College: School of Engineering	
Campus Address:				
Campus Phone: 322-7769		Fax: 322-7996	Pager:	Email: siddharth.rai@vanderbilt.edu
Complete if PI does not have campus address:				
Address: 3416 Murphy Road, Apt C12			City: Nashville	
State: TN		Zip: 37203	Phone: 615-319-7539	

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): <input type="checkbox"/> Ed.D. <input type="checkbox"/> J.D. <input type="checkbox"/> M.D. <input type="checkbox"/> Ph.D. <input type="checkbox"/> R.N. <input type="checkbox"/> Other, specify:				
Job Title:			Affiliation: <input type="checkbox"/> VU <input type="checkbox"/> Stallworth <input type="checkbox"/> VA-TN Valley HS <input type="checkbox"/> Other, specify:	
Department/Division:			School/College:	
Campus Address:				
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, 1988; 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) and physician's belief about the sources from where cancer patients get medical information. Chen Wang's survey (IRB#: 040120) which has already been approved, investigated 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. My survey will investigate healthcare professional's belief about the medical information sources that cancer patients have visited in the past and medical information sources they recommend patients 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,

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Part B. Part A investigates some background information. Part B investigates oncologists, research nurses and other care providers' belief about the medical information sources patients have visited in the past and where care providers recommend to patients to visit in the future (Please see the attached questionnaire and question citation list).

- 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 will be practicing oncologists at Vanderbilt Ingram Cancer Center and oncologists participating in the American Society of Clinical Oncology (ASCO) annual meeting to be held in New Orleans, during June 5-8, 2004. Emails will be sent to all the oncologists at Vanderbilt Ingram Cancer Center (VICC) and all the members of ASCO requesting their permission for participation. 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. Questionnaires will be given to the care providers at the conference.

- 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).

VICC- Email will be send to the oncologists which will introduce investigators to the participants, present the information letter, and describe the study. Oncologists will be asked if they are interested in participating. Survey would be send to only those oncologists who give approval for their participation in the study.

ASCO - Dr. David Dilts, Ph.D. is a member of ASCO and he has two different presentations to make during the ASCO annual meeting. We will send an Email in advance to all the members of the conference that Dr. Dilts will be attending, introducing investigators to the participants, present the information letter, and describe the study. Questionnaires will be given to the interested oncologists at ASCO annual meeting. Survey would be given to only those oncologists who will be interested in participating

- 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 list of physicians at (VICC) and care providers at the conference with inclusion criteria including: 1) oncologists, research nurses and other care providers; 2) should be treating cancer patients above the age of 18 years.

- F. Describe any procedures to be used during this study.

Investigators will introduce themselves to participants, present the information letter, and describe the study using Email. Oncologists, research nurses and other care providers will be asked if they are interested in participating. If they agree to participate, he/she will be asked complete the questionnaire. Participant 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. Participants 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#: 040120 Chen Wang's study about "Medical information sources for cancer patients," which has been approved 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.

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

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 set² 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 date 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?*	
	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	<input type="checkbox"/> Yes	<input type="checkbox"/> No
	<input type="checkbox"/> Yes	<input type="checkbox"/> 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/Form 1109DataUseAgreement.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.

Principal Investigator: Siddharth R. Version Date: 04/08/04
Study Title: Medical information sources for cancer patients- Oncologists Perspective
Institution/Hospital: Vanderbilt Ingram Cancer Center

Siddharth Rai 04/12/04
Principal Investigator's Signature Date

[Signature] 4/12/2004
Faculty Advisor (if PI is non-faculty) Date

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

Principal Investigator: Siddharth Rai
Study Title: Medical information sources for cancer patients- Oncologists perspective
Institution/Hospital: Vanderbilt Ingram Cancer Center and Conference

Version Date: 04/08/04

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.

APPENDIX F: APPROVAL LETTER FROM IRB



Vanderbilt University
Institutional Review Board

D-3232 Medical Center North Nashville, Tennessee 37232-2598
(615) 322-2918 Fax: (615) 343-2648
www.mc.vanderbilt.edu/irb

April 16, 2004

Siddharth Rai
511 Chesterfield Ave. Apt. 9A
Nashville, TN 37212

David M. Dilts, Ph.D.
Management of Technology
Box 1518, Sta. B.
Nashville, TN

RE: IRB# 040295 "Medical Information Sources for Cancer Patients-Oncologist Perspective"

Dear Mr. Rai,

A designee of the Institutional Review Board reviewed the Request for Exemption application identified above. The designee 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 16, 2004

Sincerely,


Eugene A. Gallagher, M.S.P.H., CIM, CIP
Institutional Review Board
Behavioral Sciences

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