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# Patient-oriented Evidence-based Treatment Decision Support System (TreatQuest®) for Lung Cancer

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# PATIENT-ORIENTED EVIDENCE-BASED TREATMENT DECISION SUPPORT SYSTEM (TREATQUEST®) FOR LUNG CANCER

by

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# ABSTRACT

## PATIENT-ORIENTED EVIDENCE-BASED TREATMENT DECISION SUPPORT SYSTEM (TREATQUEST®) FOR LUNG CANCER

by Danqing Hu

The University of Wisconsin-Milwaukee, 2013
Under the Supervision of Professor Hemant Jain.

Involving patients in healthcare decisions makes a significant and enduring difference to healthcare outcomes. One challenge for patients is the lack of evidence-based information and tools to support their decision making. Although patients have access to significant information through internet and other sources, it is not personalized for their specific situation. This dissertation attempts to help patients acquire evidence-based information relevant to their own situation, so they can make a more informed decision in co-operation with their physicians. Lung cancer has been selected as a focus for this study because lung cancer presents very complex decision making situation and is the leading cause of cancer deaths in both men and woman in every ethnic group worldwide. The prototype decision support system for lung cancer is called TreatQuest®. This system allows users to create their own profile, access cases similar to their case, and learn about treatment options. The evidences for the treatment were extracted from public data and knowledge gained from guideline. The effectiveness of patient-oriented evidence-based approach was validated by having a group of patient use the system. TreatQuest® is one of the first system developed to

support patient's treatment decision process, which represent the most recent trend in delivery of healthcare services. Results from this study show that such a patient-oriented decision support system provides an effective way to help patient receive more personalized information and make informed treatments. In summary, patient-oriented evidence-based decision support systems such as TreatQuest®, can improve the decision quality for patients. Also, such systems can improve health care decisions that are made with the active participation of fully informed patients. Therefore, patient-oriented evidence-based decision support systems can have significant impact on the healthcare industry.

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# DEDICATION AND ACKNOWLEDGEMENTS

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# Chapter 1 Introduction

### 1. 1 Problem Definition

Among many difficult decisions that the newly diagnosed cancer patients have to make, the toughest and also the most important is which treatment should be used. As the initial treatment bears critical consequence for the overall treatment outcome, they almost have to make the best decision right away. Unfortunately, these patients and their family will quickly realize that they are not well prepared to make such a high-stake decision, even with the help from the physicians. Most information from various educational materials or the Internet tends to be general in nature, thus offers little help for their specific cases. On the other hand, doctors usually make treatment decisions based on clinical practice guidelines and their personal experience. Research has found a large variation in their treatment practice due to the availability of clinical and demographic information (Phillips-Wren et al., 2008 [1]) as well as sensitivity to patient preference or physician and specialist supply (Starfield et al., 2005[2]; Wennberg et al., 2003[3]).

One way to help new cancer patients is through developing a patient-oriented treatment decision support system, which has actually become a new trend in health care delivery. Different from the passive role many patients used to take, patients today are better educated and more actively involved in treatment. While a number of clinical decision support systems (CDSS) and clinical knowledge management (CKM) systems have been established, their targeted users are usually not patients. Instead, their goal is to serve healthcare service

providers, such as physicians, hospitals staff, medical researchers, and members of large healthcare organizations. What is in great need is a patient-oriented support system that uses evidence-based information and industry guidelines to help patients to communicate with their physician and to make informed treatment decisions.

## 1. 2 Gaps in Research

A thorough survey was conducted for lung cancer treatment related information on popular health-related websites, including WebMD, PubMed and National Cancer Institute (NCI). As expected, these websites offer well-structured information on symptoms, types, diagnosis, tests, treatment, and care. However, no patient-oriented treatment related decision support function was found. Using these websites, patients can further educate themselves on the disease but will not be able to get information specific enough to their profile. Nor can they get substantive help in selecting an appropriate treatment.

To investigate how much treatment decision support information is available elsewhere, three popular medical support websites were examined. First, the WebMD website offers a tool called Cancer Health Risk Check. Its main function is to give a risk estimate for people who have not been diagnosed with cancer, which clearly does not apply to patients already diagnosed. Second, searching for treatment-related information for lung cancer was conducted on the PubMed website. Keywords entered included lung cancer treatment, lung cancer treatment decision support system, lung cancer treatment knowledge management system, lung cancer treatment aid system, and lung cancer therapy. The results returned were quite discouraging in that very few articles were found. The third

source is the NCI website. This website offers not only general information on different types of cancer but also summative information from Physician Data Query (PDQ), a comprehensive cancer database. This database contains summaries on a wide range of cancer topics, such as a registry of over 8,000 open and over 19,000 closed cancer clinical trials from around the world, a directory of professionals who provide genetics services, and the NCI dictionary of cancer terms and drug dictionary. In addition, PDQ also provides cancer information summaries in both patient and health professional versions for all kinds of cancer. The patient version is written in less technical language than the health professional version. While there is apparently abundant information on the NCI website, it gives cancer patients no tool or service to acquire treatment suggestions or recommendations based on their individual needs.

### 1. 3 Goals and Research Questions

To address the above gaps, this dissertation study builds a patient-oriented, evidence-based treatment decision support system to help cancer patients to make more informed decisions. This system aims to synthesize high-quality public data with specific cases, offer analytical services, and provide patients with information on multiple treatment options. The prototype system will focus on lung cancer patients but can be easily extended to other types of cancer. This system is named TreatQuest® to underscore its primary mission as the quest for treatment information. Lung cancer patients are selected as the focus as it is the leading cause of cancer deaths in both men and woman as well as in almost every ethnic group worldwide. The American Cancer Society data show that in US alone, there were 219,440 new lung cancer cases and 159,390 deaths from lung

cancer in 2009 (Jemal et al 2009 [4]). Put into a different perspective, lung cancer took 437 lives every day.

The primary goal of the TreatQuest® system is to integrate the vast amount of information on cancer in an effective way so that users can easily obtain information relevant to the characteristics of their specific case and to the kind of decisions they are going to make. To achieve this, TreatQuest® system acquires and process different types and levels of data and information. These data include the raw statistical data (e.g. the SEER data), lung cancer treatment information from relevant websites (e.g. WebMD). TreatQuest® also incorporate the latest guidelines (e.g. the National Comprehensive Cancer Network (NCCN) guidelines for lung cancer). Based on these data, functions are built to allow patients to conduct queries for retrieving disease information, similar cases, and various treatment options.

In the TreatQuest® system, the SEER data serves as the primary source. This data offer a wide spectrum of demographic information from which almost any patient will be able to find similar cases at both local and population levels. By using data mining techniques, important information can be extracted under various quest criteria. The retrieved information of similar cases can then be integrated into summarized information at the current level. For example, using the TreatQuest® system, a patient can easily look up similar cases. From there, if the patient is not certain about the sequence of treatment options, he or she can ask for information on the distribution of these similar patients on the sequence of treatments, such as the percentage of patients receiving surgery first, receiving

radiation therapy first, and receiving combined therapy. Specific information like this will guide patients in selecting an appropriate treatment plan.

The focus of this study is on the development and evaluation of the TreatQuest® system from both theoretical and practical perspectives. Specifically, the following research questions are addressed:

1. How can a patient-oriented decision support system with evidence-based information and knowledge help patients to make informed decisions?

2. How to develop a patient-oriented decision support system that is based on large-scale data and industry guidelines?

3. How to evaluate the effectiveness of a patient-oriented decision support system?

## 1. 4 Significance of the Study

Newly diagnosed cancer patients need both standardized and customized information to make informed treatment decisions. While the standardized information can be obtained from various guidelines, online resources, and educational materials with considerable ease, the much-needed customized information is hard to come by. The real power of the TreatQuest® system lies in the high-quality customized information that it is able to generate. Such a system will help to alleviate the stress and anxiety that many patients experienced accumulate in searching for the optimal treatment option. More importantly, it will present reliable unbiased medical information in a language that patients can understand and use.

TreatQuest® can also complement the guidance and services that

healthcare providers currently offer. This system will greatly improve patients' engagement and involvement, which has been shown to be indispensable in cancer treatment. Utilizing a semi-structured decision support system and the latest standards in evidence-based medicine, patients and caregivers are in a good position to share the current and case-specific information with the physicians, who in turn, will have better chance to deliver the most appropriate treatment.

# Chapter 2 Literature Review

## 2.1 Patient Involvement as a Global Trend

The rapid advances of information technology along with the dramatic social and legal changes in the healthcare industry have promoted a higher degree of involvement of patients in the medical decision making process. As a result, more and more research has been devoted to the question on how to increase patient participation. According to a recent review published in the journal Cochrane Database of Systematic Reviews, conducted in the United States(Kinnersley et al., 2011[5]), patients who participated in informed decision-making were 20 percent less likely to choose costly surgery over medication than other patients. In Belgium, an investigation of 128 advanced cancer patients in 13 hospitals (Pardon et al., 2009 [6]) revealed that almost all patients were interested in obtaining more information on diagnosis, treatment, cure rate, and life expectancy. Some patients also wanted information on palliative care (63.5%) and end-of-life decisions (56.8%). This study clearly indicates that while the need of patients may vary, they all want to be better informed. In Japan, a study conducted by Watanabe and Takahashi (Watanabe et al., 2008 [7]), investigated the actual preference of Japanese people on the involvement in treatment decision making. Cancer patients recruited from a cancer self-help group in Tokyo were interviewed on how they made decisions on cancer treatment. This study finds that patients' views on their preferred role in the decision making process can vary substantially from complete physician control to complete patient control. Overall, the patients with more control over their decision are more satisfied. One key factor that affects the satisfaction level is how well the preferred involvement

has been met by the actual involvement. This study suggests that to increase patient satisfaction, healthcare professionals should assess individual patient preferences first and provide healthcare services accordingly. Moreover, an environment should be created to facilitate patients in expressing their preferences.

A joint effort by researchers from Australia and the United Kingdom (Gaston and Mitchell 2005[8]) systematically reviewed what information was given to and what decisions were made by patients with advanced cancers. The results show that almost all patients express the desire to be given all the information. Meanwhile, about two-thirds expressed the interest in actively participating in decision-making. Higher educational level, younger age and female gender were indicative of stronger desire to participate. Active decision making was also found to be more common in the patients with certain cancers (e.g. breast) than others (e.g. prostate). This study concludes that the past 40 years has witnessed a shift from treating patients as passive recipients to active consumers who demand a higher level of autonomy. This study uncovers many benefits of involving patients in health-care decisions, such as better compliance with treatment and increased satisfaction of both patients and healthcare providers. Possible disadvantages are the extra time and therefore higher cost, inflated patient anxiety and regret in cases that an adverse outcome ensues as a result of a patient-driven decision.

Researchers from the United Kingdom (Elwyn et al., 2000[9]) interviewed experienced general practitioners on their attitude towards patient involvement in decision making and on the necessary contextual factors, competencies, and

stages to achieve satisfactory shared decisions. These clinicians listed interpersonal skills and information requirements as major obstacles to shared decision making. In addition, they viewed involvement as an implicit ethos that should permeate medical practice. Their study result indicated that experienced general practitioners with educational roles have positive attitudes to the involvement of patients in decisions, provided the process matches the role individuals wish to play.  Besides that, Bekker (Bekker, 2010 [10]) studied how the use of International Patient Decision Aids Standard (IPDAS) collaboration checklist affected patients in making treatment choices. These authors show that IPDAS has been promoted as an aid to help professionals engage in shared and/or patient-centered care and its domain has been established mainly by experts' opinions of best practice.

In summary, cancer patients have been shown to have a higher level of desire and perceived participation in medical decision making than other patients (Ernst et al., 2010 [11]). It is increasingly common for them to take a more active role in the decision making process.

## 2.2 Shared Decision Making

The most commonly cited and generally accepted conceptualization of shared decision making was defined by Charles (Charles et al., 1997[12]). These authors define the key features of shared decision-making as 'involvement of both the patient and the doctor, a sharing of information by both parties, both parties taking steps to build a consensus about the preferred treatment, and reaching an agreement about which treatment to implement'. Over the past few decades, the paternalistic health care style has gradually fallen out of favor. Instead, the

patient-centered model has become a new norm (Stewart and Brown, 2001[13]). The patient-centered model emphasizes patient autonomy, informed consent, and empowerment.

The shared decision making (SDM) work is also part of the evidence-based medicine movement starting from the 1980s. This movement focuses on providing evidence about medical alternatives to healthcare providers and patients in order to improve their decision-making. This movement has received high level of policy support in many countries (Coulter, 2001[14]; Coulter and Ellins, 2006 [15]). On the other hand, doubts have also been cast on whether the shared decision-making can be applied to all patients (Brundage et al., 2005 [16]; Deber et al., 2007 [17]; Edwards et al., 2005[18]). Other researchers have also questioned its practicality in some situations (Berry, 2007[19]; Towle et al., 2006[20]).

Shared decision-making has led to the birth of new organizations, conferences, projects, and standards. For example, the primary mission of the International Shared Decision Making (ISDM) Conference is to create ethical standards for informed consent and to provide technology assessment for shared decision making and patient-centered care (Margaret, 2008 [21]). The meetings of the Society for Medical Decision Making and the International Society for Technology Assessment in Health Care (ISTAHC) are extra venues for researchers to share idea on SDM. Organizations such as the Institute for Health Sciences (IHS) and European Association for Communication in Health Care (EACH) have interests in shared decision making as well. As a collaborative enterprise, the International Patient Decision Aid Standards (IPDAS) aims to

identify research gaps, perform basic research in decision science and cognition, support a set of criteria to be applied to patient decision tools, and stimulate development of the field.

While increased patient involvement and shared decision-making have been shown to be beneficial in many ways, such as better quality of care, higher satisfaction for both patients and healthcare providers, and improved self-esteem for patients (Crawford et al.,2002 [22]), in practice, they are not widely adopted (Carlsen and Aakvik, 2006 [23]). Major barriers to their implementation include attitudes, skills, and time availability for the providers (Gravel et al., 2006 [24]). As always, decision-making process for health professionals is highly influenced by personal preferences, experiences, relationships, and structural constraints arising from class, education, ethnicity, and culture (Longo et al., 2006 [25]). On the patients' end, their experience may also vary by situation. Consequently, some of them may take contradictory or ambivalent stands on assuming responsibility for their health and health care at different times and/or different situations.

### 2.2.1 Physician's Perspectives

Previous studies have found significant variability in how physicians view the involvement of patients in medical decision making. First of all, not all physicians favor patient involvement (Bruera et al., 2001 [26]). What is suggested is that rather than forcing a uniform approach on all patients, physicians should directly ask patients about their preferred level of involvement. Second, external factors such as gender, geographical region, culture, and family background can all exert influence on patient decision making (Baile et al., 2002[27]). For example, women have been shown to be easier to discuss about hospice referral

than men. They are less likely to withhold prognosis from the family. Lastly, experienced general physicians with educational roles have more positive attitudes towards the involvement of patients in decision making (Elwyn et al., 2000 [28]) than those not engaged in education. These physicians are more ready to take a cooperative approach in solving clinical problems.

In general, one consensus is to let patients decide how much information should be shared and how much family involvement is appropriate. In practice, providers should ask directly and early how the patient would like information to be shared. This patient-focused approach not only empowers patients but also relieves physicians from taking all the responsibility for the treatment outcome.

### 2.2.2 Patient's Perspectives

Evidences suggest that patient's preferences for receiving information on treatments and for taking responsibility for treatment decisions vary as well. Preference for a more active role is associated with increased level of education, younger age, and female gender (Gaston and Mitchell, 2005[8]). Active decision-making was more common in patients with certain cancers (e.g. breast) than others (e.g. prostate). Degner (Degner et al., 1997 [29]) has found that 22% of women with breast cancer wanted to select their own treatment, 44% wanted to select their treatment in collaboration with their physician, and 34% wanted to delegate this responsibility totally to their physician. A post-treatment survey found only 42% believed they had achieved their preferred level of control in decision making and approximately 15% believed they had been pushed to assume a more decisional role than they wanted.

Researchers in Canada has also investigated the response of lung cancer patients about their desired and actual levels of involvement in treatment decision and about information needed for treatment decision-making (Davidson et al., 1999 [30]). They found 43% of patients desired a collaborative role in their real treatment decision at the beginning of treatment. After the treatment, 57% of patients desired an active or collaborative role. Generally, patients wanted a wide variety of information on treatment options. Types of information rated as 'essential' to treatment decisions were details of the treatment regimen, early and late side-effects, survival, and effects of treatment on disease symptoms. These findings are in sharp contrast with results from a study in Germany, where 60.2% of patient actually desired a more passive role with hematological disease (Ernst et al., 2010 [11]). In other words, the majority of the patients would rather leave their medical decisions to physicians.

In conclusion, many cancer patients prefer an active role in their treatment. The desire of involvement is affected by factors like disease type, disease stage, age, gender, education level, as well as family involvement.

### 2.2.3 Evaluating Shared Decision Making

While SDM is viewed by many as the gold standard for medical care (Charles et al., 1999 [31]) and there is evidence that SDM does lead to positive patient outcomes (Gattellari et al., 2001 [32]; Fallowfield et al., 1990 [33]; Street and Voigt, 1997[34]), others have argued that SDM is not always realistic or preferred by patients (Butow et al., 2006 [35], Lam et al., 2003 [36]). As the concept of SDM is relatively new, not many instruments have been published to evaluate its effectiveness.

SDM should be viewed as a flexible approach for patient participation with different levels of applicability, contingent upon settings, time, and patient preference (Mazur and Hickman, 1997[37]). With regard to measurement issues, both generic and disease-specific instruments should be used to capture the results from different angles(Miller, 1995 [38]). Generic instruments can be applied to many types of diseases and may also be less costly (Deber, 1996 [39]). However, changes in generic measures can be hard to interpret and they may not be sensitive enough to detect small changes in specific populations or diseases (Miller, 1995 [38]), which can be picked up by more specific instruments (Katon, 1981 [40]).

In recent years, a number of SDM coding systems and measures have been published, such as the Decision Support Analysis Tool (DSAT) (Guimond, 2003[41]), the Observing Patient Involvement (OPTION) scale (Elwyn, 2003 [42]), the Decision Analysis System for Oncology (DAS-O) scale (Brown et al., 2003 [43], the Shared Decision-Making Questionnaire (SDM-Q) (Simon et al., 2006[44]), the Autonomy Preference index (API) (Ende et al., 1989 [45]), the Control Preference Scale (CPS) (Degner and Sloan,1992 [46]), the Patients' Perceived Involvement in Care Scale (PICS) (Lerman et al., 1990 [47]) and the Combined Outcome Measure for Risk Communication and Treatment Decision Making (COMRADE) (Edwards et al., 2003[48]). These coding systems share common characteristics but each also has its own uniqueness.

Many behaviors were similarly coded in the OPTION, DAS-O and DSAT systems. The DAS-O and OPTION coding systems explained a significant moderate proportion of the variance in satisfaction with the doctors' SDM

skills(Butow et al., 2009[49]).The DSAT has been developed primarily to code decision support provided outside the medical consultation, but many aspects of this coding system relate to issues regarded as important in SDM within the consultation, including presenting options, discussing the pros and cons of these options, and eliciting patient preferences and values. According to Weiss et al (Weiss and Peters, 2008[50]), DAS-O was strongly correlated with OPTION. DSAT was moderately correlated with DAS-O and OPTION. Decisional satisfaction and satisfaction with doctor SDM skills were significantly correlated with OPTION and with DAS-O.

In general, these systems have not been able to deliver satisfactory results. One possible reason is the variability in patient preferences for shared decision making is confounded with whether or not they are satisfied with consultation altogether. One exception is the satisfaction measures used in the oncology setting, where highly skewed distributions have been observed with most patients expressing extremely high satisfaction scores (Brown et al., 2008 [51]).

Since not all coding systems are equally valid, it is important to ensure that optimal systems are used in analyzing doctor and patient behaviors. Meanwhile, while shared decision making by nature involves both clinicians and patients, coding systems designed for health practitioners should not be used for patients. At present, not many instruments focus on both parties (Braddock et al., 1999 [52]). To obtain a comprehensive evaluation of SDM, instruments and coding systems that analyze both doctor and patient behaviors need to be combined.

## 2.3 Current Status of SDM

### 2.3.1 Models of Decision Making in Medical Care Context

In studying the patient's role in medical decision making, especially in handling the conflict between autonomy and health, between the values of the patient and the values of the physician, different models of making healthcare decisions have been proposed. Elwyn et al (Elwyn et al., 1999 [53]) has modeled the clinical decision-making as a spectrum from a paternalistic model at one end to the informed choice model at the other end (Charles et al., 1997[54]). In the middle of this spectrum lies the model of shared decision-making (Figure 2-1).

Paternalistic ◄─► Shared Decision-Making ◄─► Informed Choice

Figure 2-1: Spectrum of Patient Clinician Interaction

The paternalistic model is also known as the parental or priestly model. This model obliges patients to seek 'expert' help and to comply with the medical regimen. It is a model where physicians do what is thought best for patients without necessarily eliciting the latter's input. The 'informed choice' decision-making model stands on the opposite end of the spectrum. This model, also known as the 'consumer model', describes a process whereby patients receive information from their physicians about treatment choices but they will make the final decisions on the treatment. Under this model, a patient's values will be well defined and appreciated. It is the physician's obligation to provide the patient with all medical information relevant to the disease and available interventions. The patient then has both the information required and the personal preferences necessary for decision-making. One concern about the 'informed choice' model is the possible high anxiety level the patient may feel due to the sole responsibility

in decision making (Quill and Brody, 1996 [55]). In the extreme case, they may feel being abandoned by the doctor. While vastly different, neither the paternalistic model nor the informed choice model involves both physician and patient simultaneously in the clinical decision making process, giving room to a more compromised model.

The shared decision making model, by definition, represents a process in which physicians and patients share decision making. This model has attracted more and more attention and been advocated as the ideal model for physician-patient interaction. In addition to ethical reasons that have prompted the use of SDM, there is also growing evidence that this is the approach most patients desire for.

Research has shown that when patients take a more active part in making decisions about their care, treatment outcomes turn out to be better. One example is the achievement of improved diabetic control in studies by Greenfield, Kaplan and Brody (Greenfield et al., 1988[56]; Kaplan et al., 1989[57], Brody et al., 1984[58]). Recent work also reveals the complexity that underlies the apparent relationship between patient involvement and improved health outcomes. Street and Voigt (Street and Voigt, 1997[59]) demonstrates that the patient's perception of decision control is a key issue with both stable and dynamic characteristics, depending on the patient's personality, their involvement within the consultation, and the eventual health outcome. Huygen et al (Huygen et al., 1992[60]) shows that certain types of consulting styles could improve the health of patients across a practice list. There will also be times when patient preferences will be in direct conflict with clinical guidelines. One classical example is the wish to receive

antibiotics for viral illnesses. These conflicts may threaten doctor–patient relationship (Bradley, 1992 [61]) and health outcomes (Little et al., 1997 [62]). Shared decision-making will need to accommodate such contradictory beliefs. Stewart (Stewart et al., 1997[63]) reported that where patients 'perceived' that they had achieved 'common grounds' with physicians, there were fewer demands on laboratory and referral services. To sum up, potential positive outcomes from the shared decision model are the provision of clear information, input from patients, shared information and shared decisions, agreement between the patient and the doctor on problems and the treatment plan, and finally, a positive and reliable relationship between the patient and physician.

**2.3.2 Characteristics of Shared Decision Making (SDM)**

The essence of a shared decision making includes two broadly defined aspects: sharing information and sharing decision. Sharing information and sharing decisions are not synonymous (Ong et al., 1995 [64]).They have separate goals and require different skills. Shared decision-making will not happen unless preceded by the sharing of information. Charles et al (Charles et al., 1997[12]) summarized the four characteristics of shared decision making process as follows. First, shared decision-making involves at least two participants — the doctor and the patient — and often many more, such as patient family or professional colleagues. Second, both parties take steps to participate in the process of treatment decision-making. Third, information sharing is a prerequisite to shared decision making. Fourth, a treatment decision is made and both parties agree to the decision.

In the shared decision making model, information sharing is of utmost importance. It requires an open two-way exchange of information and opinions about probabilistic data so that medical decisions will be made based on a better understanding of options and outcomes. This process cannot occur within a doctor-centered consultation. Instead, consultation has to be patient-centered (Stewart et al., 1995 [63]). Such a consultation is also known as 'risk communication' for the fact that the patient is given information with unknown impact. The information can affect the patient's decision either positively or negatively. In that sense, while doctors are increasingly aware of the need to inform patients about treatment options and encourage patients to be more involved, they should also disclose the benefits and risks associated with each treatment. At the same time, individual choice can be sensitive and involve value judgments. Same treatment effect may be interpreted as trivial by some patients but as significant by others.

Sharing information based on patients' needs can reduce the risk or negative impact and maximize the benefits of patient-centered medical care. For example, as mentioned above, a sizeable minority of cancer patients prefer to relinquish decisional control, particularly if faced with a dire prognosis. Advocating active patient involvement for those patients would endanger, rather than engender, patient autonomy. Given the current emphasis on patient participation, understanding patient preferences can determine what kind of information to share, how much information to share, and to what degree the information should be shared.

### 2.3.3 Strategies of Shared Decision Making (SDM)

As SDM requires a commitment from both patients and physicians, strategies for the advancement of SDM have either focused on patients, physicians, or both. For patients, the use of patient decision aids (PDAs) is a well-acknowledged and increasingly popular means to prepare for SDM. For physicians, SDM training programs are offered to improve SDM skills. The training programs along with PDAs have greatly facilitated SDM in medical consultations.

For physicians, research (Loh et al., 2007 [69]) has found that the SDM training is attractive to a broad range of physicians and most physicians displays a positive attitude towards it. Most SDM trainings orientate around a set of SDM core competencies, defined in the framework for SDM (Brody et al., 1989[66]; Street and Viugt, 1997[34]). These competencies exceed the basic communication skills in that advanced skills are required for partnership-building, risk presentation, discussion of evidence-based information, and explicit dialogue.

The effectiveness of SDM training was evaluated in Elwyn et al.(Elwyn et al., 2004[67]). The clinicians in that study demonstrated greater involvement of patients in treatment decision making after participating in skill development workshops. It appears that the most effective way to increase clinicians' abilities to involve patients is to familiarize them with detailed information before discussing skill development techniques. After the workshop, the clinicians were able to integrate the risk communication aids by using the graphical illustrations in scheduled review consultations with real patients after the training intervention. As part of a national German research consortium called ''Patients as Partners in

the Medical Decision Making Process,'' (Loh et al., 2007[68]), a clinical trial was conducted to explore the possibility of implementing SDM training for physicians in practice. Results suggest that for the SDM training be attractive to a broad range of physicians. Overall, physicians from 13 specialties signed up for the training. Higher interest was observed in the more "people-oriented'' specialties, such as family medicine, probably due to the fact that physicians in those fields tend to value the physician–patient relationship more than their counterparts in more ''technology-oriented'' specialties. Approximately 94% of the participants in that sample showed a positive attitude towards SDM. This result is consistent with other studies showing SDM is the most well respected interaction model among physicians (Murray et al., 2007 [69]; Charles et al., 2004[70]).

Although most physicians view SDM favorably, the actual use of SDM lags far behind the ideal implementation level. As a result, many patients do not feel involved to the desired extent. It seems that though physicians are motivated and like the idea of SDM, they are not well prepared to implement it yet. When physicians choose to adopt a SDM model, they are faced with the challenge of providing patients with information and making shared decisions with them. All these require advanced SDM communication skills that may not be present yet. This suggests that more efforts should be put into disseminating SDM training and new tools should be developed  so that information like risks and benefits can be shared more easily.

As a patient-centered model, shared decision-making has the potential to improve patients understanding and satisfaction, patient adherence, and a reduction in the use of resources such as laboratory services and referral.

However, with more patient's involvement comes new responsibilities, such as evaluating risks and benefits of each treatment. Patient Decision Aid or PDAs have been introduced to help patients analyze such risks and benefits. The interest in PDAs has been rising. The next section will be devoted to the review of the utility of PDAs in SDM.

**2.4 Decision Aids**

**2.4.1 Concept of Decision Aids**

Decision aids commonly refer to tools that are designed for patients or people facing healthcare decisions. They aim to help people deliberate, independently or in collaboration with others, about options. This is usually done by considering relevant attributes in forecasting short, intermediate, and long-term outcomes and consequences. Healthcare providers may also use decision aids as adjuncts to prepare patients for decision making. Decision aids usually provide descriptive information on the disease or condition, probabilities of outcomes tailored to a person's health risk factors, an explicit clarification of values exercise, information on others' opinions, and guidance in the steps of decision making and communicating with others. Decision aids may be administered with the use of various media, such as brochures, videotapes, decision boards, interactive videodiscs, interactive computer programs, audiotapes, audio-guided workbooks, pamphlets, and group presentations. Excluded from the definition of decision aids are passive informed consent materials, educational interventions that are not geared to a specific decision, and interventions designed to promote compliance with a recommended option rather than a choice based on personal values.

### 2.4.2 Types of Decision Aids

Although all decision aids provide information on the benefits and risks of treatment options, the difference lies in how the information is presented. Some are interactive and others are non-interactive. Interactive decision aids use interactive multimedia programs such as videodisks, computer programs, and personal interviews. Non-interactive decision aids use more traditional media, such as decision boards, videos, brochures, posters, pamphlets, written vignettes, written materials, and checklists, prompt lists, other consultation session based, scripted counseling, and audio-guided workbook.

### 2.4.3 Utility of Decision Aids

Decision aids aim to provide accurate, balanced, and tailored information to help patients improve their knowledge and skills in shared decision making. For example, using the probability of different treatment outcomes computed by a decision aid, patients can form a more realistic expectation of treatments (Tversky and Kahneman, 1981[71]). They can express their thoughts in the terms familiar to physicians (Fischhoff et al., 1980[72]). With functions which provide by decision aid, they will help patients handle the uncertainty in choosing treatment options with more confidence (O'Connor, 1995 [73]). Decision aids offer one of the most effective means to ensure that patients are informed about their treatment options. These aids can come in the form of a brochure, video, interactive website, or a combination, and they provide balanced, evidence-based information about medical conditions, the patient's treatment options and the tradeoffs involved in each option. High-quality decision aids can help patients understand

their various options and the potential outcomes within the context of their own preferences and values.

### 2.4.4 Efficacy of Decision Aids

Considerable research has been devoted to studying the efficacy of decision aids. Overall, results have been positive. Decision aids have the potential to increase the likelihood that choices are based on better knowledge, realistic expectations of outcomes, and personal values for cancer patients. Annette et al (Annette et al., 1999[74]) reviewed published evidence on the efficacy of decision aids on cancer treatment outcomes. They summarized the evaluative studies from the annotated bibliography (O'Connor et al., 1999[75]) by searching databases like MEDLINE®, CINAHL®, PsycINFO®, and Current Contents®. They also manually searched Medical Decision Making and Health Expectations. Three types of studies were included. The first type was before/after studies that evaluated decision aids with patients at the point of decision making. The second type was randomized trials that evaluated decision aids in comparison to "usual care" with patients at the point of decision making. The third type was randomized experiments comparing different methods of decision support in decision aids either with patients at the point of decision making or with volunteers making hypothetical choices. Their research results indicate that cancer-related decision aids are acceptable to patients and especially helpful to those who are uncertain in making decisions.

Stacey el al (Stacey et al., 2008[76]) conducted randomized trials of cancer patient decision aids. They conclude that patients exposed to decision aids are more likely to make higher-quality decisions. Randomized trials of patient

decision aids were also studied in Annette and O'Connor(Annette and O'Connor, 2007 [77]).Their findings include that decision aids can increase knowledge, lower decisional conflict, and encourage more active patient participation in decision making. However, decision aids have impact on patient anxiety and satisfaction level during the decision making process.

### 2.4.5 Implementation of Decision Aids

The implementation of decision aids is based on decision theories from economics and cognitive psychology (Stacey et al., 1997[76]; Annette et al., 2007[77]; Keeney et al., 1976[78]). These theories describe decision making by options, outcomes, and probabilities of outcomes so that patients can make value judgment on the benefits versus the risks. Many decision making frameworks broaden this cognitive perspective by including emotional, social, and environmental dimensions (Tversky et al., 1981[79]; Fischhoff et al., [80]; Janis et al., 1977[81]; Orem, 1995[82]; Norbeck, 1988[83]). For example, the Ottawa Framework (O'Connor  et al., 1998[84]) identifies several determinants of health care decisions that may be modifiable by decision aids. The goal is that the decisions made are more likely to be: 1) informed (i.e., based on better knowledge and realistic expectations), 2) consistent with personal values, and 3) actually implemented. In clinical practice, successful implementation of patient decision aids requires access to the interventions, practitioners' awareness and skills in using those interventions, and environmental structures that support their use (Graham and Logan, 2004 [85]).

The Cochrane Inventory of Patient Decision Aids has over 500 decision aids. Out of this huge inventory, about 200 are currently available (Stacey et al.,

2008 [86]).These aids come from both academic institutions and health

information organizations. Examples of the cancer-related aids are available from

the Foundation for Informed Medical Decision Making (www.fimdm.org),

Healthwise (www.healthwise.org), the Mayo Clinic(www.mayoclinic.org), and

the Ottawa Health Research Institute (www.ohri.ca/decisionaid) which also

provides a personal decision guide and an interactive tool to explore different

decisions.

Given the variable quality of the available patient decision aids, a group of

experts from 14 countries established a consensus on a set of criteria for judging

their quality (Elwyn et al., 2006[87]). These criteria are categorized into the

domains of essential content, development process, and evaluation. The

International Patient Decision Aid Standards (IPDAS) is available as a checklist

(www.ipdas.ohri.ca) and is currently being used to rate the quality of patient

decision aids that are publicly accessible. These quality ratings are available at

www.ohri.ca/decisionaid(see Decision Aid Library Inventory). The IPDAS

checklist was designed to be used by developers, patients, health care

professionals, health care insurers, administrators, policy makers, and researchers

to critically appraise individual decision aids or to compare across available

decision aids on the same topic.

Patients can access most current decision aids directly on the Internet or

through the help from health care professionals or disease-specific community

resource programs (O'Connor,Wennberg  and Légaré, 2007 [88]). For example,

several cancer programs have integrated decision aids and decision quality

measures within the process of care for women with breast cancer considering

treatment options (Silvia and Sepucha, 2006 [89]; Kearing et al., 2006[90]). In primary care, cancer screening decision aids have also been incorporated into routine medical visits (Brackett et al., 2007[91], Brooks et al., 2006[92]).

Access to Decision Aids can have substantial impact on patient decisions. (Kennedy et al., 2002[93]). A systematic review of more than 80 randomized controlled trials found wide differences between the choices made by patients facing elective decisions who had access to decision aids versus patients who received usual care – who were informed by their providers.(Stacey et al., 2011[94]).  Compared with patients who got usual care, patients who had access to a decision aid were better informed about their treatment options; more satisfied with their decision; experienced less discomfort, greater reduction of symptoms and more improvement in general medical conditions; had less conflict about the decision once they made it; and were 20% less likely, on average, to choose the more invasive option. There was no difference in outcomes among the groups.

As stated above, access to decision aids tool should be considered when we build decision aids tool for patient. Considering this, a web-based internet site which allow patient to access from their home or clinic at any time will be developed as a decision aid format. This computer program will be implemented as a decision support system for patients. More details on the decision support system are given in Section 2.5.

**2.5 Decision Support System**

**2.5.1 Concept of Decision Support System (DSS)**

A decision support system aims to support making business or personal decisions. Technically speaking, a decision support system (DSS) is an interactive knowledge-based, software information system. Such a system compiles the information from multiple sources, such as raw data, documents, guidelines, and scientific models, in solving problems and making decisions.

## 2.5.2 Type of Decision Support System

No universally-accepted taxonomy has been established for DSS. Depending on whether the system uses knowledge or not, DSS can be roughly classified as knowledge-based or non-knowledge-based. From the user's perspective, DSS can be labeled as passive, active, or cooperative. A passive DSS is a system that aids the process of decision making, but does not bring out explicit decision suggestions or solutions. A cooperative DSS uses an iterative process between system suggestions and user modification. After the system provides decision suggestions, the decision maker can modify, complete, or refine them and the system will use the new input to generate new suggestions. This process iterates until a consolidated solution is reached. Using the mode of assistance as the criterion, Power (Power, 2002 [95]) differentiated DSS systems as being communication-driven, data-driven, document-driven, knowledge-driven, and model-driven. In short, a communication-driven DSS supports more than one person working on a shared task. A data-driven DSS or data-oriented DSS emphasizes access to and manipulation of a time series of data. A document-driven DSS manages, retrieves, and manipulates unstructured information in a variety of electronic formats. A knowledge-driven DSS provides specialized problem-solving expertise stored as facts, rules, procedures, or in similar

structures. Finally, a model-driven DSS emphasizes access to and manipulation of a statistical, financial, optimization, or simulation model.

### 2.5.3 Decision Support System in Healthcare Domain

Based on decision support theory, a DSS can be built in almost any knowledge domain. The healthcare domain has witnessed quite a growth in DSS applications, concepts, principles, and techniques. One DSS system is the Clinical Decision Support System (CDSS), which has been defined as "Clinical Decision Support Systems link health observations with health knowledge to influence health choices by clinicians for improved health care" by Dr. Robert Hayward of the Centre for Health Evidence. This definition underscores two important features of CDSS. First, CDSS is knowledge-based. Second, it is functional. CDSS incorporates interactive computer programs to achieve the function of assisting physicians and other health professionals with their decision making tasks.

CDSS can provide support to decision making at various stages in the healthcare process from preventive care through diagnosis and treatment to monitoring and follow-up. In a clinical setting, different decision support systems have been developed for different stages. The most common use of CDSS at present is to meet clinical needs of achieving accurate diagnoses. Such CDSSs aim at the diagnostic tasks in the care process, hence known as Diagnostic Decision Support System (DDSS). Examples of DDSS systems are DXplain, Iliad, Meditel, QMR (The book 'Clinical Decision Support System: Theory and Practice' which was written by Et S. Berner, chapter 5). The performance of these systems was evaluated in Berner et al. (Berner et al., 1999 [96]).

Another popular use of CDSS is to provide physicians and pharmacies with convenient prescription ordering systems. These systems bear different names like Clinical Physician Order Entry, Computerized Physician Order Entry or Computerized Prescriber Order Entry, all abbreviated as CPOE. In essence, COPE is a process of electronic entry of medical practitioner instructions for the treatment of patients (particularly hospitalized patients). These instructions are communicated over a computer network to relevant constituents of the healthcare, including hospital staff, pharmacy, laboratory and radiology, which are responsible for fulfilling the order. Using a computerized system decreases delays in order completion, reduces clerical errors such as those due to handwriting in transcription, allows order entry at the point-of-care or off-site, provides error-checking for duplicate or incorrect dosages or tests, and simplifies inventory and posting of charges. Statistics have shown that CPOE are able to reduce the general medication error rate by 80% and errors with serious potential patient harm by 55% (Colpaert et al., 2006[97]). Other studies have also suggested extra benefits of CPOE, such as automatic dosage alerts (e.g., letting the user know that the dosage is too high and thus dangerous) and interaction checking (e.g., telling the user that two medications taken together could cause health problems).

CDSS can also be tailored for particular conditions or types of patients. Such a system will have access to guidelines and other external databases so that it can provide specific information to those patients. It can also be programmed to send reminders for preventive care and alerts about potentially dangerous situations.

To sum up, CDSS can lower cost, improve efficiency, and reduce inconveniences. In ideal cases, CDSS can address these three issues simultaneously. One such example is alerting clinicians to potentially duplicative testing. For routine tasks, such as presentation of a predefined order set, CDSS can relieve the clinician from the burden of reconstructing orders for each encounter. For more complex tasks, such as diagnostic decision making, the aim of CDSS is to assist, rather than to replace, the clinician. In that case, CDSS will offer suggestions and the clinician will filter the information, review the suggestions, and then decide what action to take.

**2.5.4 Gap in Decision Support System for Patient**

Despite the wide range of clinical decision support systems that have been implemented by institutions and pharmaceutical companies, no such decision support system has been developed with patients as primary users. In other words, patients have been treated as passive receivers of medical decisions. Based on our large-scale review as discussed in introduction section of this writing, no CDSS is available for patients yet. Actually, even the definition of CDSS suggests that their target users are clinicians and physicians, not patients. There are systems that can help patients keep track of their personal health records, such as Microsoft Vault and Google Health. However, they are more in line of a data repository with no decision support functionality. As primary stakeholders of medical decisions, patients have yet to be given adequate consideration in the CDSS system development.

This huge gap is the main motivation for us to conduct this study. The main goal of this research is to develop a DSS that is patient-oriented rather

clinician-oriented. This DSS aims to provide patients and their family with important and specific information on the disease (e.g. lung cancer). With the help of this system, patients will be able to play a more active role in the shared decision making process.

## 2.6 Patient-Oriented Evidence-Based Decision Making

Modern medical care has been influenced by two paradigms: patient-centered medicine and evidence-based medicine. These two paradigms have gained momentum rather rapidly. Today, both of them play an important role in daily clinical decision making. Patient-centered medicine puts a strong focus on patient participation by taking into account the patients' perspective in tuning medical care to the patients' needs and preferences. The uniqueness of each patient, such as individual needs, preferences, and emotional status, are emphasized as relevant factors in decision-making. Evidence-based medicine, on the other hand, focuses on offering the best available evidences about the most adequate treatment. These two paradigms are highly relevant, but yet seem to have operated separately. One challenge is how to bring them together. Actually, both paradigms can benefit from interchanging ideas and principles with each other. The primary goal of TreatQuest® is to integrate these two paradigms in a seamless manner. Patient involvement and evidences for treatment options will be combined, which is the main motivation for the concept of patient-oriented evidence-based decision making.

The most important feature of a patient-oriented approach is that it provides information that matters to patients. Patients need the help of a decision support system that actually understands their needs and is able to provide the

tailored and customized information by screening out irrelevant information. A patient-oriented decision support system must meet the following two basic criteria: the system must be able to address possible questions that patients encounter and the system must have the power to help them make decision. Patient-oriented decision support systems aim to help patients generate insights into the decision process. They achieve this goal by educating patients about the options and outcomes for the disease, assessing their preferences for the outcomes and revealing the implications of treatment options. Throughout this process, the system can also help patients understand how other patients had been treated and what outcome they have received (Scott et al., 1999 [98]).

The term 'evidence-based medicine' (EBM) is relatively new but its origin can be traced back to ancient Greek and Chinese medicine. The history of EBM can be roughly divided into four eras: ancient (before the 17th century), renaissance (from the 17th to the 19th century), transitional (1900-1970's), and modern (after 1970's) (Claridge & Fabian, 2005[115]). The ancient era consists of historical and anecdotal accounts of what may be loosely termed as EBM. In the renaissance era, one important figure of EBM is Thomas Beddoes, who was a reforming practitioner, a teacher of medicine, and an associate of leading scientific figures. In the book called "A Letter to the Right Honourable Sir Joseph Banks, Bart. P. R. S.: On the Causes and Removal of the Prevailing Discontents, Imperfections, and Abuses in Medicine" that he coauthored with Joseph Bank, he proposed to cite scientific objections (Beddoes & Banks, 1808[116]).

It is during the transitional era of EBM that a model of ecology of medical care was proposed by White and colleagues in 1961 (White et al., 1961[117]).

This model shows a valid perspective of medical care use in the 1960s. It organizes the complex relationships known to affect health care and the health of populations and states their implications for the organization of health care, medical training, and research. The model has also stated geo-demographic and socioeconomic status as factors influencing health care use. Despite substantial changes in medicinal care in recent years, such as the improved techniques for data collection, a reassessment of health care use by the ecology model has actually shown similar structures to those in the 1960s.

In the modern era of EBM, the term "evidence based" was first used by David Eddy in 1990 and the term "evidence-based medicine' first appeared in the medical literature in 1992 in a paper by Guyatt and colleagues(Guyatt et al., 1992[124]). The methodologies used to determine "best evidence" was first established by a research group at McMaster University led by David Sackett and Gordon Guyatt(Sackett et al., 1993[125]; Sackett et al.,1994[126]). Sackett actually defined EBM as "the integration of best research evidence with clinical expertise and patient values" (Sackett et al., 1996[119]).

Along with the growth of evidence-based medicine, more attention has been paid to patients' expectation and request from healthcare services (Kravitz, 2001[120]). For example, a classification system, TORP, was set up to understand the links between patients' unarticulated desires and expectations, patients' verbal requests, physicians' provision of health care services, and patients' and physicians' perceptions of the visit (Kravitz, Bell & Franz, 1999[121]). The TORP system features 11 categories of requests for patient information and 8 categories of requests for physician action. Using the TORP system helps

researchers and healthcare providers identify the most common forms of patient requests as well as the most successful clinical negotiations to meet those needs. As another example, Mayor (Mayor, 2004[122]) illustrates the process and components of a decision for patient in the evidence-based medicine setting, as in Figure 2-2. The figure clearly shows how to make decisions based on the best current evidence while taking into account the knowledge about the particular patient or services under consideration.
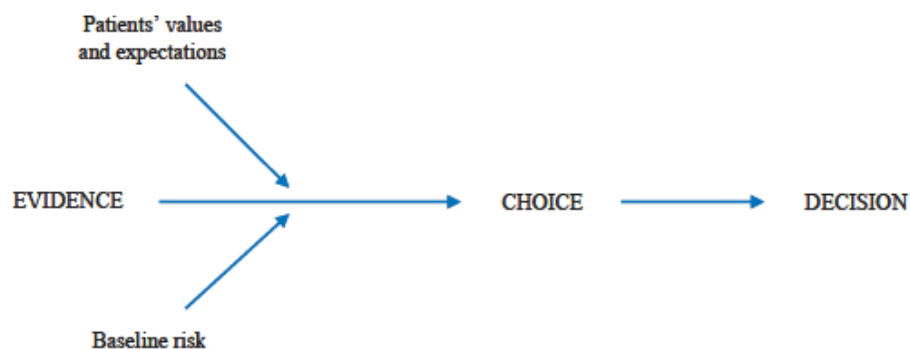


Figure 2-2 Patient Decision Making Process in Evidence-Based Medicine

As an information-rich enterprise, EBM has been radically transformed by technology advances. A greater and more seamless flow of information within a digital health care infrastructure can be delivered and compensated by incorporating electronic health records (EHRs) /electronic medical records (EMRs), which also opens up the possibility of developing better clinical decision support system and of providing cost-effective treatments for patients. For example, the Intermountain Project designed by Intermountain Healthcare, Inc. was able to offers high-quality care while reducing costs through using technology to heavily computerize the healthcare services (November, 2011[123]).

Evidence-based decision making is another equivalent important aspect of the patient-oriented evidence-based decision making concept. It involves the explicit, conscientious, and judicious consideration of the best available evidences in making health care decisions (Alejandro, 2000[99]).  Evidence-based decision making is supported by a rapidly evolving set of methods and tools. Applications that support the consumer's role in decision making has become a strong focus in the United States (Clancy, 2005 [100]). Consumers are looking for high-quality evidences to answer their questions. Those evidences offer them scientific information to make correct decisions. Hence, whether a patient can make evidence-based decisions relies on whether the patient has access to evidence-based information. An evidence-based decision support system can make such information extremely handy by providing patients with access to up-to-date and valid knowledge at the right time, at the right place, in the right amount, and in the right format (Eysenbach, 2001 [101]). Moreover, this service will be delivered in a low cost, fast, and effective manner.

The TreatQuest® system intends to provide an evidence-based platform that is built with many kinds of knowledge resources. Mainly, three types of evidences will be included: similar case analytical results based on the SEER data, clinical practice guidelines, and scientific papers published in peer-reviewed journals. Using these evidences, patients will become more educated about treatment options. They can also discuss with physicians on what the guideline currently offers, what clinical research have shown, and what the SEER data have found. This way, patients will receive the strong support at the time of decision making. As the information gap between patients and clinicians have been greatly

narrowed, patients can be more engaged and informed in the treatment decision making process. By bridging the patient-centered medicine with the evidence-based medicine, the TreatQuest® system aims to improve the overall quality of healthcare.

# Chapter 3 Methodology

This dissertation study employs both quantitative and qualitative research methods. Section 3.1 describes the overall research design, including the stages and the methods. Section 3.2 describes the data structure of the TreatQuest®. The detailed design of TreatQuest® is given in Section 3.3.

## 3.1 Research Design

In order to design a practical, accountable, and effective decision support system for patients, the system development life cycle (SDLC) model will be implemented. In software engineering, the SDLC concept underpins many software development methodologies. These methodologies form the framework for building the patient information system for this study. The SDLC model can be divided into five phases. As illustrated in Figure 3-1, these phases are analysis, design, implementation, testing, and evaluation. In applying this framework to our study, the first step is to analyze the needs of patients so that the functions of TreatQuest® can be defined. Based on those functions, the architecture of TreatQuest® is then designed. This covers all the desired features of TreatQuest®, such as system diagram, data model, process chart, and personalization logic. In the implementation phase, software code is written and the whole system will be built. It is at this stage that the design of TreatQuest® is actually translated into a complete web-based system. Finally, in the testing phase, functional testing, evaluation, and validation activities will be conducted to examine how patient actually use or like the system. Their feedback will also be used iteratively to further improve the system.
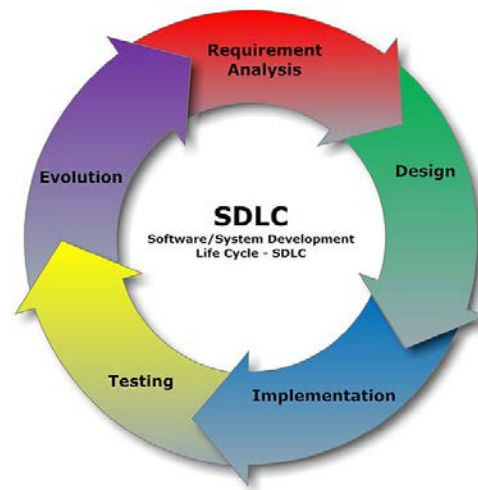
Figure 3-1 Model of the Systems Development Life Cycle

## 3.2 Data Source

Cancer data may be collected by Health Management Origination (HMO), government, and no-profit organizations. All these data sources can be used in TreatQuest®. They are referred as external data to differentiate from the data collected by TreatQuest®. There are two options to use the external data. One is to access those data by using web services or specific software offered by data providers, the so-called on-demand access. One drawback of this option is that data access will be restricted by a third-party service, such as the web services or software functions. A better option seems to store the external data in the TreatQuest® system so that it is always available. This requires first to gain the license to use the data as well as to load the data properly into the repository. This option gives TreatQuest® more freedom in conducting queries. Once we have a copy of those external data, it is more flexible to retrieve and gather information based on the needs. The disadvantage of this option is we have to load the data into our repository first. But once the data is loaded, we can query and

manipulate the data easily, so useful information can be generated based on our needs.

In TreatQuest®, the second option was adopted. Figure 3-2 illustrates the internal data repository of TreatQuest®. At the top of the chart is the data source, which includes the possible external data as listed in the external static data source box. TreatQuest® makes a copy of these data and stores them in the repository. In addition to the external data, the TreatQuest® internal repository also features research literature, guidelines, and patient data collected by TreatQuest®, referred as internal data in the figure. The internal data consist of both user information and patient information. User information includes user name, password, email, and security related information. Patient information includes demographic information, diagnose information, staging information, and histology information, which can be used to build dynamic queries to retrieve treatment-related information.  With all these data, TreatQuest® internal processing engine can easily retrieve relevant data and information from the internal repository in generating dynamic query results to users. For example, using the collected patient information and the SEER data, similar cases can be retrieved and analyzed for a user.

Moreover, TreatQuest® can retrieve data and information that resides outside of TreatQuest®. Those data are referred as external data repository at the bottom of Figure 3-2. By adapting Google customized search function, TreatQuest® external processing engine can gather information and display them in TreatQuest® without going to those external websites. This way, users can easily retrieve information from external websites, such as WebMD. In addition

to the search function, links to those data are also provided. Figure 3-2 also shows how TreatQuest® uses internal data repository. By combining the information from the internal and external sources, TreatQuest® provides hybrid information to the end users, who can then use various criteria in conducting dynamic queries. In this sense, TreatQuest® could be viewed as hybrid, dynamic data, information and knowledge resources for patients.
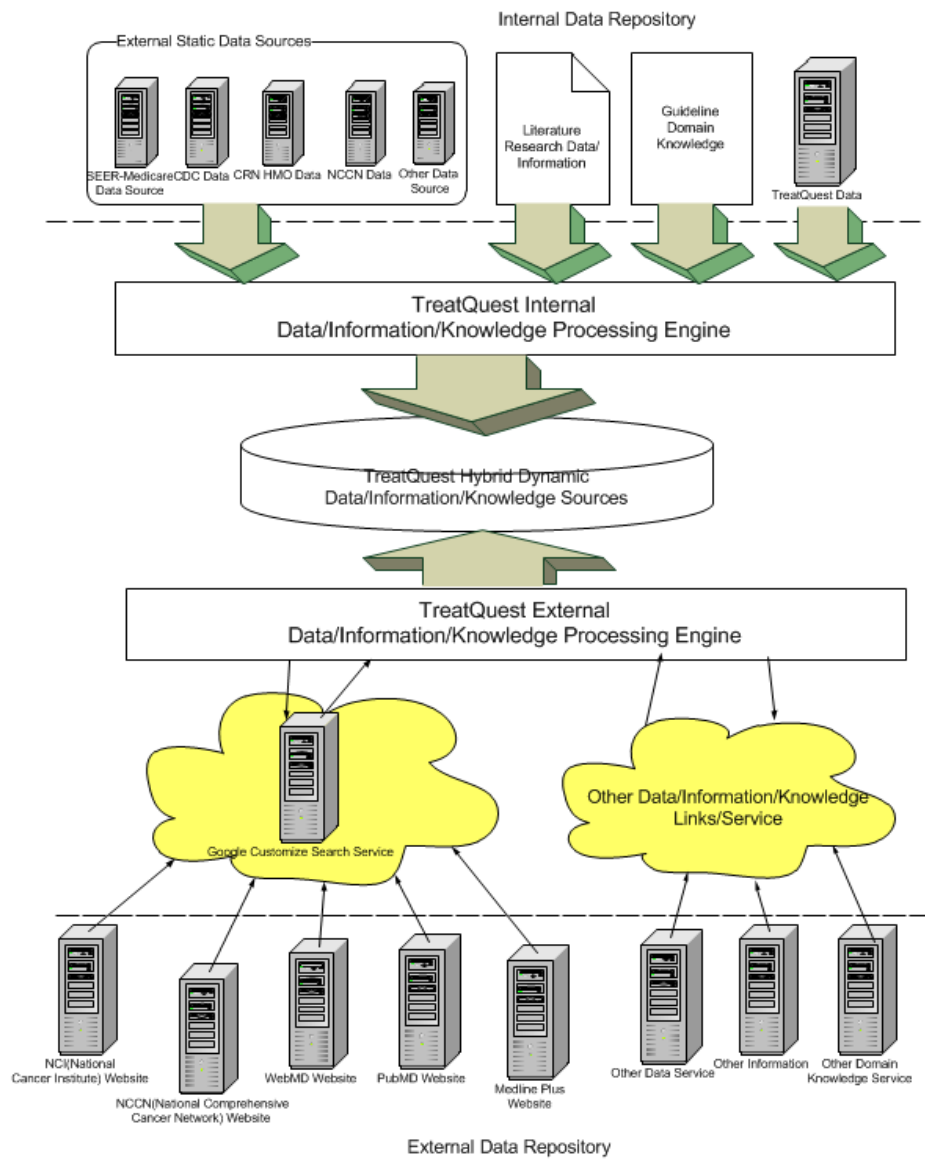


Figure 3-2    TreatQuest® Data/Information Organization

### 3.2.1 SEER Data

The Surveillance, Epidemiology, and End Results (SEER) program is offered by National Cancer Institute (NCI), which has collected and published cancer incidence, prevalence, and survival data from population-based cancer registries since 1973. SEER data is unique in that it covers approximately 26 percent of the U.S. population. The SEER registries routinely collect data on patient demographics, primary tumor site, tumor morphology, stage at diagnosis, and first course of treatment, and they follow up with patients for vital status. Moreover, the SEER Program is the only comprehensive source of population-based information in the United States that actually collects information on the stage of cancer at the time of diagnosis. It also provides patient survival data for the analysis of longitudinal trends. By using SEER data, it is possible to provide population level cancer related case match for site and stage of disease.

SEER data consist of 124 data items. A detailed description of all items is given in the Appendix A. The original SEER data file is in the text format.  In order to use such a large SEER dataset in TreatQuest®, both data load and data preprocessing process were implemented. The data load process reads a SEER file and inserts it into a temporary database table. The data preprocessing inserts the necessary data items from the temporary database table to the TreatQuest® tables. By these two steps, SEER data will be used more effectively and efficiently in TreatQuest®.

### 3.2.2 Data Load

SEER data comes with a structured directory in the ASCII text format. Based on different cancer sites, data from different SEER registries are stored in

different data files. Figure 3-3 is an example of the directory structure and files of respiratory cancer data from different SEER registries. To use these SEER data as internal repository, they have to be imported into the TreatQuest® system.

| FilePath | FileName | FileType |
|---|---|---|
| .SEER_DATA\SEER_1973_2008_TEXTDATA\incidence\yr2000_2008.ca_ky_lo_nj | RESPIR.TXT | FLAT TXT FILE |
| .SEER_DATA\SEER_1973_2008_TEXTDATA\incidence\yr1992_2008.sj_la_rg_ak | RESPIR.TXT | FLAT TXT FILE |
| .SEER_DATA\SEER_1973_2008_TEXTDATA\incidence\yr1973_2008.seer9 | RESPIR.TXT | FLAT TXT FILE |
| .SEER_DATA\SEER_1973_2008_TEXTDATA\incidence\yr2005.lo_2nd_half | RESPIR.TXT | FLAT TXT FILE |

Figure 3-3   Example of SEER Data Directory Structure

To load the SEER ASCII text format data file, a SSIS package has been developed. The control flow of this SSIS package is shown in Figure 3-4.  By running this SSIS package, all related information from SEER data sources can be loaded and stored as tables.

Following that, a database named SEER_Data_Load was created, which will serve as the host of SEER data and information. In essence, this loading process converts the original SEER data elements into the database columns in the TreatQuest® database tables so that patient cases will be represented in a consistent manner. This practice enables the query of similar patient cases, which is a crucial component of our system. The original SEER data file has information on patients diagnosed from 1973 to 2008 and lung cancer research data are stored in the filed named RESPIR.TXT in each sub-directory. Using the SSIS package, all the lung cancer related data from year 1973-2008 have been loaded into the SEER_Data_Load database.

### 3.2.3 Data Preprocessing

Data preprocessing is an important step in data mining and data analysis. Examples of data pre-processing functions are cleaning, normalization,
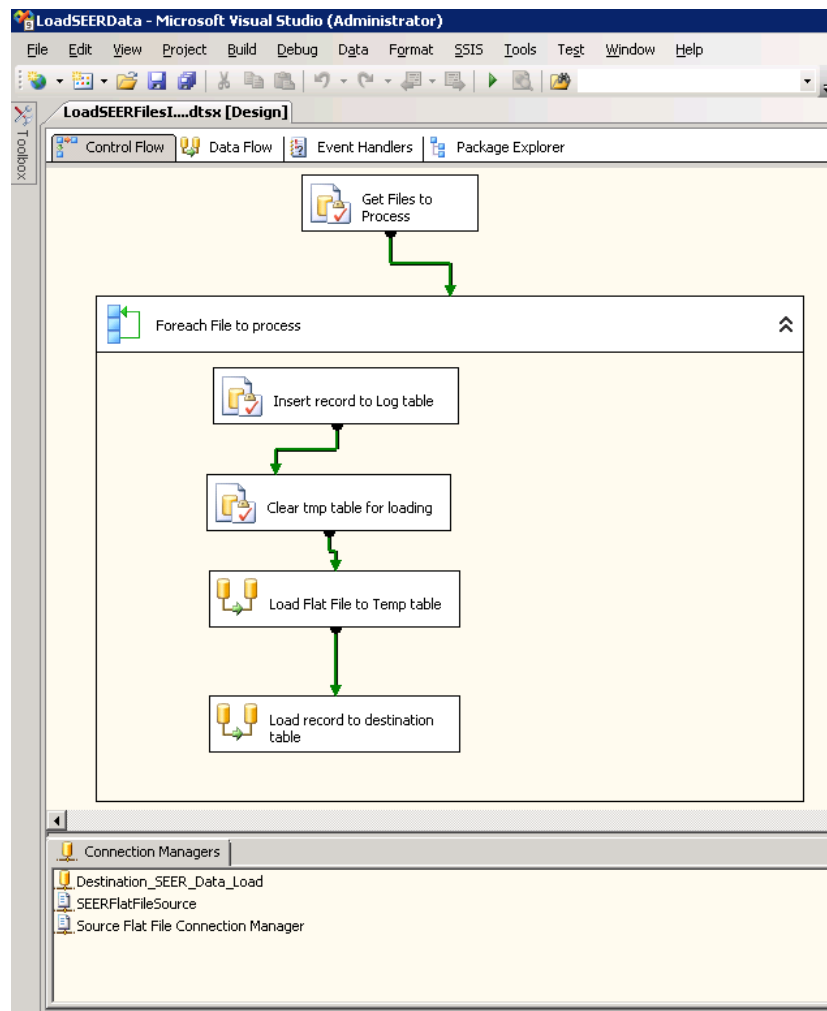
Figure 3-4   Control Flow of SEER Data Load
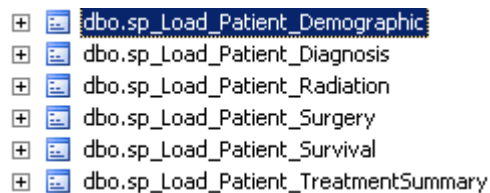
transformation, and selection. As described above, the data loaded into

SEER_Data_Load database are loosely controlled, thus additional data

preparation and filtering steps are necessary to remove noisy, redundant, or

unreliable data.

Not all 124 data items in the SEER data were collected for all years. For

example, the data item of RX Summary - Surgery Primary Site is only available

after year 1998. Another example is that data item RX Summary – Surgery Type

was collected from 1973 to 1997 only. More importantly, new items were added

after 2004, especially those items such as tumor size, lymph node, and metastasis

required for derived AJCC (American Joint Committee on Cancer) staging information. As these items bear significant importance in developing a patient support system, this study used the SEER data after 2004 only.

Based on the clinical domain, data items that are essential for representing a patient's ontology information are identified. Those items can be categorized as demographic information, diagnosis information, treatment related information (e.g., surgery and radiation), and survival information. To represent and store them more efficiently, data items are grouped into different database tables with each item being a table column.

To complete the data preprocessing, a series of stored procedures were developed and implemented, as shown in Figure 3-5. These procedures import the filtered and converted data from SEER_Data_Load database to the final destination in the TreatQuest® database.



```
⊞ 🖳 dbo.sp_Load_Patient_Demographic
⊞ 🖳 dbo.sp_Load_Patient_Diagnosis
⊞ 🖳 dbo.sp_Load_Patient_Radiation
⊞ 🖳 dbo.sp_Load_Patient_Surgery
⊞ 🖳 dbo.sp_Load_Patient_Survival
⊞ 🖳 dbo.sp_Load_Patient_TreatmentSummary
```

Figure 3-5  Example of Stored Procedure for Data Preprocessing

Tables with patient information are: Patient_Demographic, Patient_Diagnosis, Patient_Surgery, Patient_RadiationTherapy,  and Patient_Survival. Figure 3-6 is a screenshot of those tables.
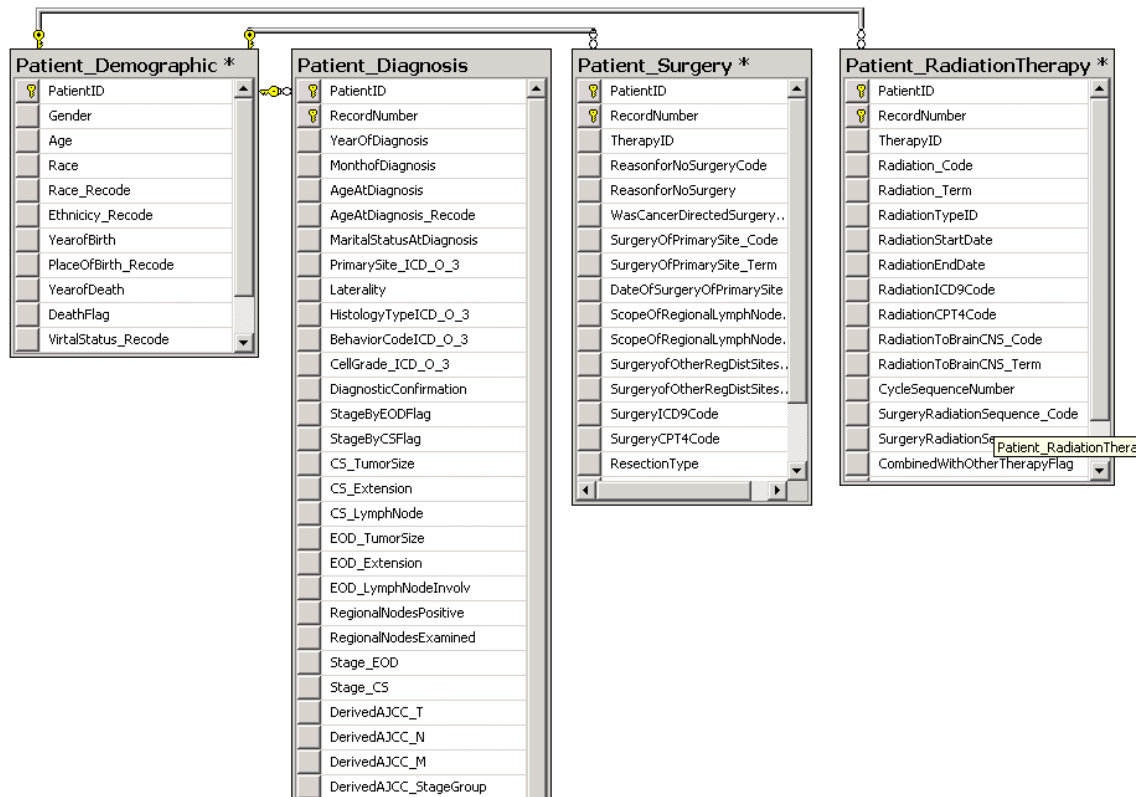
Figure 3-6 Tables in TreatQuest® after Data Preprocessing

## 3.3 TreatQuest® System Design

System design is a process of defining the architecture, components,

modules, interfaces, data model, and process flow for a system to satisfy specified

needs. It can also be viewed as the effort to develop an application from a

theoretical model. This section will describe the technical details of TreatQuest®.

Topics covered are selection of the structural elements and their interfaces,

behaviors as specified in collaboration among those elements, composition of

structural and behavioral elements, functionality, usability, and special features

incorporated into the system.

### 3.3.1 Architecture of TreatQuest®

TreatQuest®is designed as a web application by using tools like Microsoft

ASP.Net, Microsoft Internet Information Server, Microsoft Windows Server and

Microsoft SQL Server. It works in web browser such as Microsoft Internet

Explorer.  Figure 3-7 shows the logical architecture of TreatQuest®.
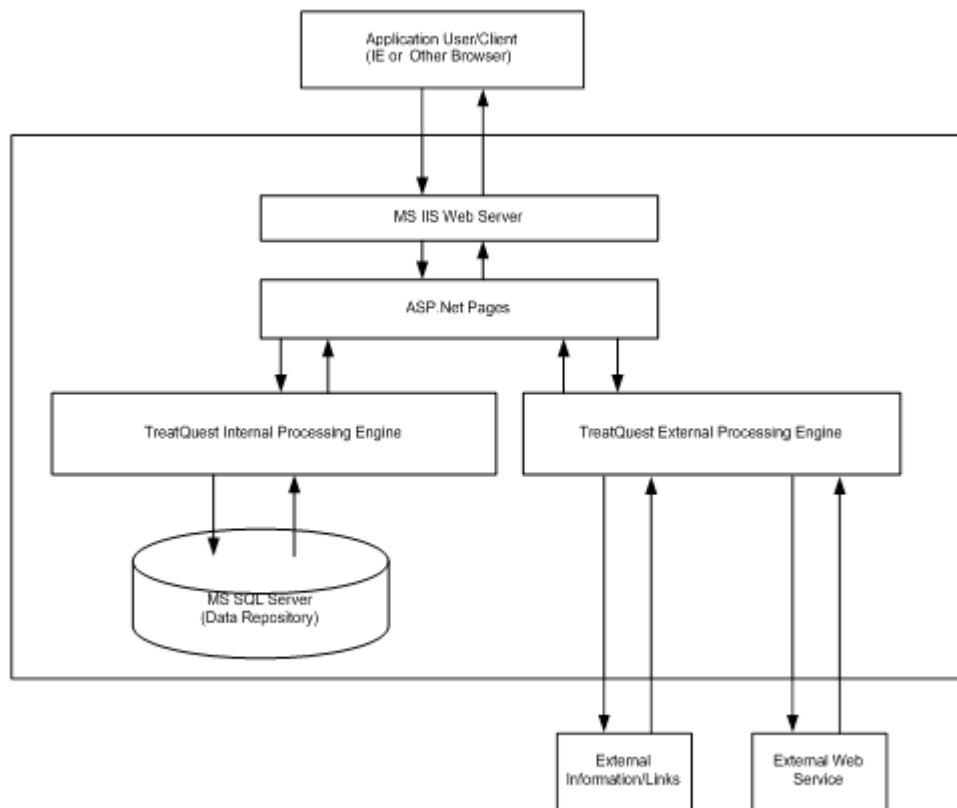


Figure 3-7 Architecture of TreatQuest®

Microsoft SQL Server is the software used as database management

system. Raw data, processed data, and information and knowledge are stored in

the corresponding databases of SQL Server. Query processing is divided into

internal and external processing. The internal processing engine retrieves the

query results from internal data repository and the external engine handles queries

to external data sources. Both internal and external results are combined in the

results and returned to the user simultaneously. The IIS Web Server is used to

process requests submitted from the user's browser. For external information and

knowledge query, web service technology was adapted to retrieve external information.

### 3.3.2 Process Flow of TreatQuest®

This section describes how TreatQuest® system typically processes an inquiry using the illustration in figure 3-8. Suppose a user is interested in obtaining the treatment information of all the cases that are similar to his or her case, or the so-called similar case query. When TreatQuest® server receives such a request, it will send the request to the TreatQuest® processing engine. The engine translates the query to a corresponding data query and a knowledge query and retrieves the result from the TreatQuest® internal data repository. Direct answers will be generated by the SQL query. More sophisticated answers will trigger more steps in data processing, data mining, and knowledge acquisition.
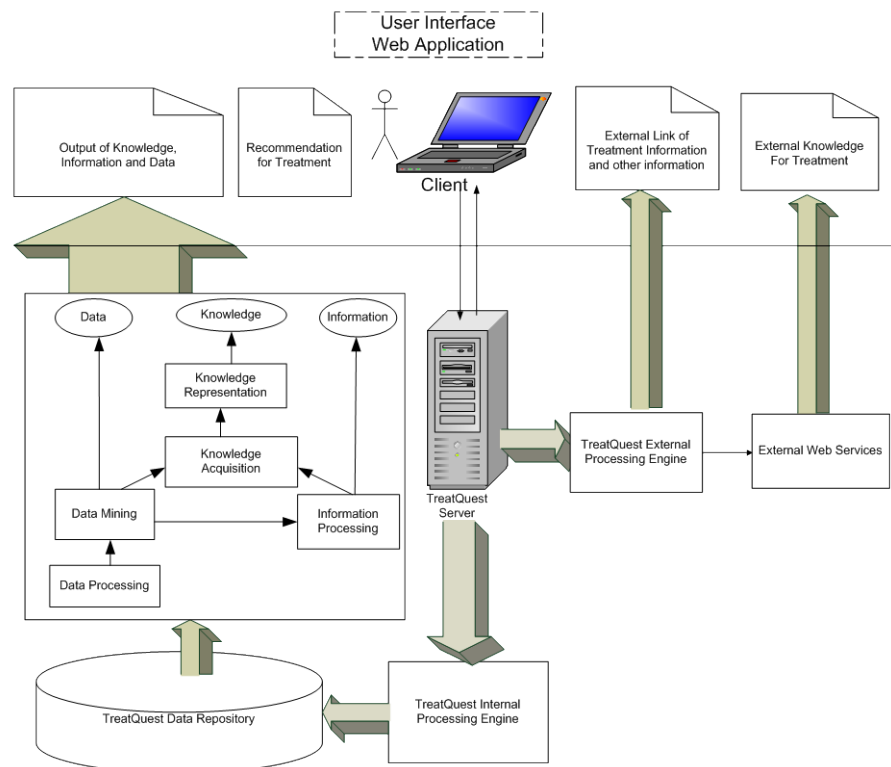


Figure 3-8   Process Flow of TreatQuest®

Meanwhile, TreatQuest® external processing engine will send a web service call to the external web service server. Results from the internal and external engines will be combined and returned to the user.

### 3.3.3 Personalization and Tracking Patient Profile

In order to keep track of the profile of a patient, different tables were created in the TreatQuest® database. At the frontend, users can submit their information via web based user interface. At backend, the information will be stored into the database. TreatQuest® stores user preferences by asking such information at registration and saving it in cookies. When a returning user is detected, the system will invoke the profile to personalize the use of the system.

The personalization and tracking process is illustrated in Figure 3-9.
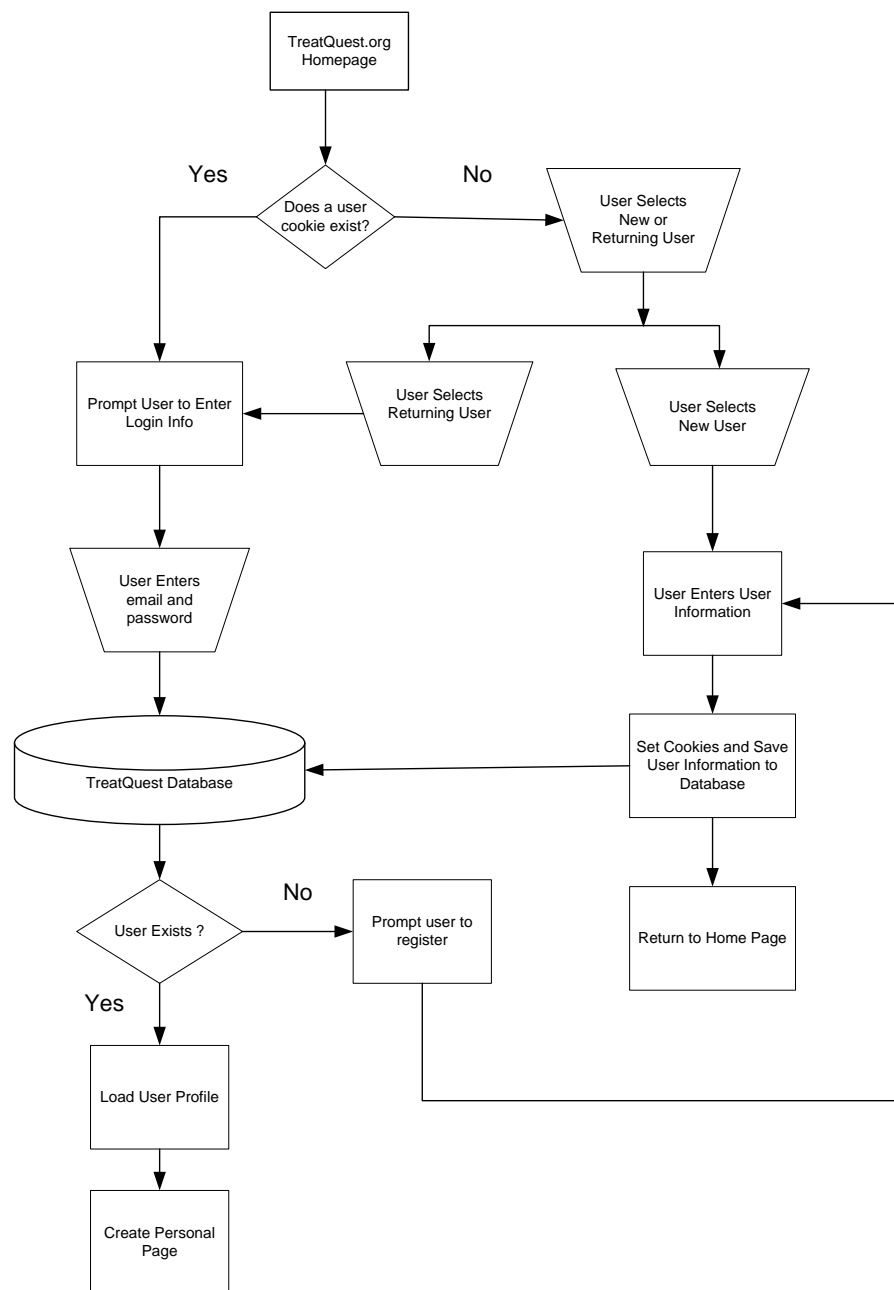
Figure 3-9  Personalization and Tracking Process in TreatQuest®

**3.3.4 Data Model of TreatQuest®**

The backend of TreatQuest® consists of databases that store data,

information, and knowledge. These databases consist of multiple layers.  In other

words, several layers of data and information are either stored in one database or

distributed among multiple databases. The lowest layer stores the original

information while the higher layers stores more general information extracted from the lower layers.  For example, the SEER_Data_Load database described in section 3.2.3 is at the lowest layer with only the original data.

Data in TreatQuest® are classified as primitive and high-level data. The former is actual data and the latter resides at the higher levels of the concept hierarchy. Correspondingly, a primitive-level query is a query whose constants involve primitive data only, whereas a high-level query is a query whose constants involve high-level data. To retrieve results at different levels, a query can be defined either at the primitive or high level. Both primitive data and high-level data can be aggregated or summarized according to different queries.

TreatQuest® is implemented as a web portal that provides services to its users. At the minimum, new visitors should be able to create an account and returning visitors should be able to log in. Most of pages or services are available only to the logged in users and as described above, information is personalized in some pages. For example, patients diagnosed with stage I lung cancer will see the Treatment Wizard for Stage I cancer only. Likewise, only treatment option for stage I will be offered to these patients. That is also to say, they will have customized access to treatment wizards based on the cancer stage.

### 3.3.4.1 Security Model

Security is a very important aspect of TreatQuest®. Patient/user information needs to be kept confidential under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and Health Information Technology for Economic and Clinical Health of 2009 (HITECH) Act. Personal information can

be modified by the patient only so that information integrity will be maintained. This section will discuss the security features implemented in TreatQuest®.

In order to secure the TreatQuest® website, ASP.NET Membership service database was installed. The ASP.NET Membership service offers functions like authentication, authorization, user accounts, and user roles. Figure 3-10 is the schema of the Membership database.
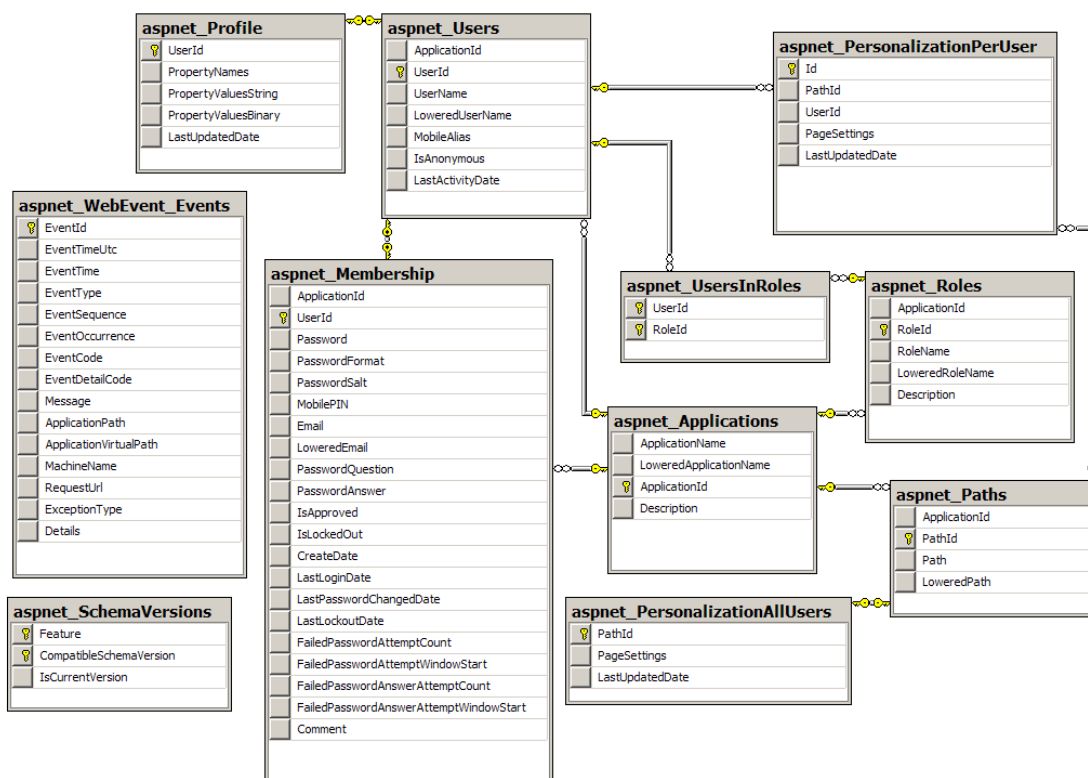


Figure 3-10     ASP.NET Membership Database Schema

Using ASP.NET Membership service and the login controls in ASP.NET gives TreatQuest® a powerful and convenient way to validate users by a database. The membership service has been implemented in the following four steps. First, a membership database named aspnetdb is created in SQL Server. Second, specification of membership option is enabled. Third, the type of membership is

determined and configured in TreatQuest®. Lastly, user membership account and configuration roles are defined.

### 3.3.4.2Authentication via Forms Authentication

Authentication is the process of ascertaining the client's identity. A client who has been successfully identified is said to be authenticated whereas an unidentified client is anonymous. A secure authentication system embodies at least one of the following three facets: something one knows, something one has, or something one is. Most web applications rely on something the client knows, such as password or PIN. The information used to identify a user, such as username and password, is also referred to as credentials.

Forms authentication has been a popular way of securing web applications. Forms authentication identifies a user by prompting him or her to enter the credentials through a web form. Consequently, when a user attempts to access an unauthorized resource, he or she will be automatically redirected to the login page where credentials can be entered. The submitted credentials are then validated against a database with the user information.

After the submitted credentials are verified, an authentication ticket will be created for the user. The ticket is usually stored as a cookie on the client computer. Subsequent visits to the same website will activate the ticket in the HTTP request, thereby enabling the web application to recognize the user once they log in.

Figure 3-11 illustrates the forms authentication workflow from a high-level vantage point. Notice that how the authentication and authorization pieces in ASP.NET act as two separate entities. The authentication system identifies who

the user is or reports the anonymous status. The authorization system then

determines whether the user has access to the requested resource. For the

unauthorized user (such as those attempting to anonymously visit

ProtectedPage.aspx in Figure 3-11), the authorization system will report that the

user is denied access, triggering the forms authentication system to automatically

redirect the user to the login page. Once the user has successfully logged in,

subsequent HTTP requests will carry a forms authentication ticket for the

authorization purpose.
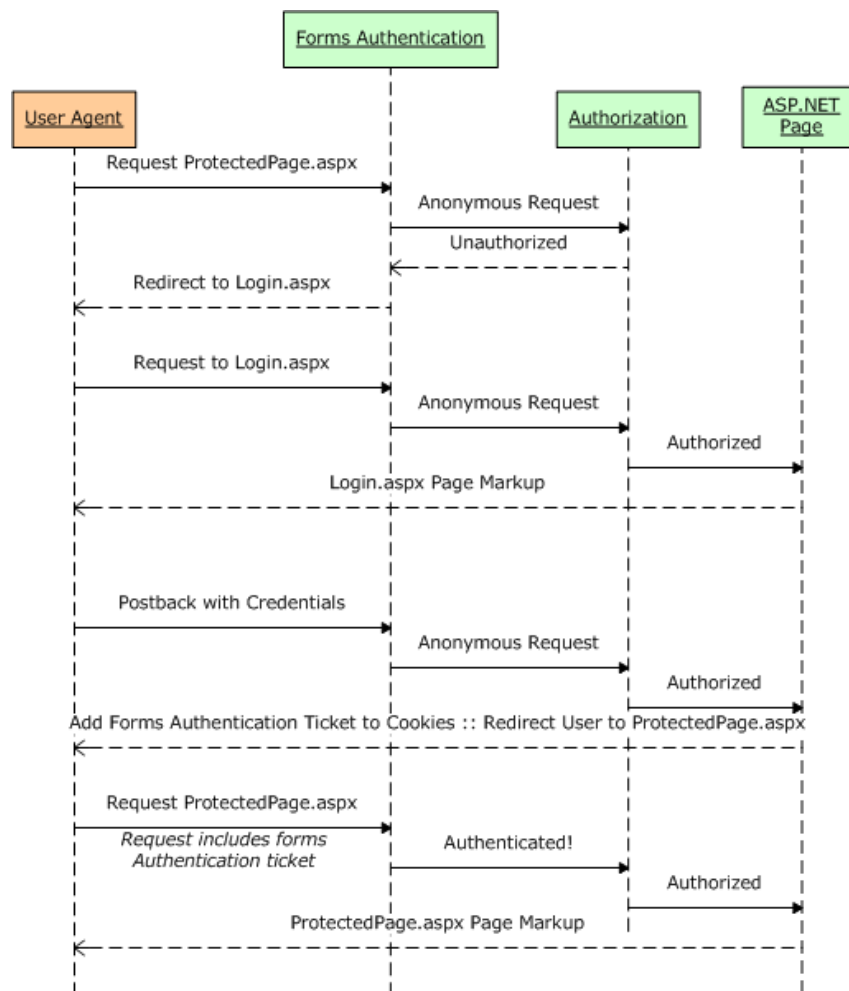


Figure 3-11: The Workflow of Forms Authentication

### 3.3.4.3 Authorization, User Account and Roles

In addition to identifying clients, a server may need to limit the resources or functionalities for certain requests. Authorization refers to the process of determining whether a particular user should have the authority to access a specific resource or functionality. A client must have a user account in order to access the protected pages in TreatQuest®. A typical user account includes the information a user needs to log in and use a system. A user account stores persistent information about a particular user. It must minimally include information that uniquely identifies the user, such as the user's login name and password. Along with this essential information, user accounts may include things like the user's email address, the date and time the account was created, and the date and time last logged in. In TreatQuest®, user account information is stored in a relational database at backend by Microsoft SQL Server.

Web applications that support user accounts may optionally group users into roles. A role is simply a label that is applied to a user and provides an abstraction for defining authorization rules and page-level functionality. For example, a website might include an administrator role with authorization rules that prohibit anyone but an administrator to access a particular set of web pages. Moreover, a variety of pages that are accessible to all users (including non-administrators) may display additional data or offer extra functionality when visited by users in the administrator role. This way, authorization rules can be defined by role rather than by user. In TreatQuest®, administrators and the public are the two main roles specified. Figure 3-12 gives an example of extra functionalities that is offered to the administrator. The administrator can select a specific user account to make

changes like role setup, update, and account deletion. As illustrated in figure 3-13,

the administrator of TreatQuest® can easily manage a user account in the system.
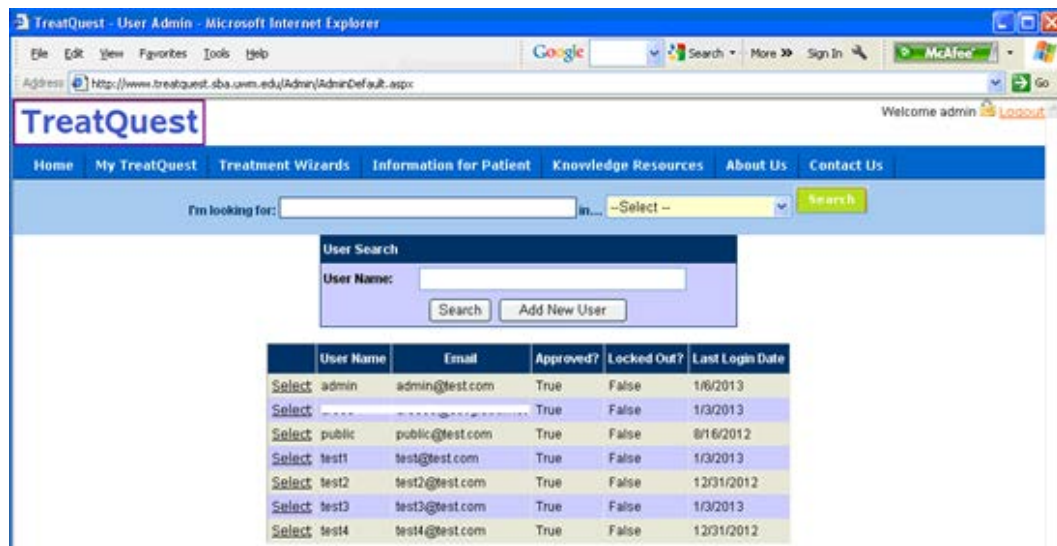


Figure 3-12 Functionalities for Administrator in TreatQuest®



Figure 3-13 User Account Management by Administrator in TreatQuest®

### 3.3.5 Patient Representation in TreatQuest®

In creating a disease-related profile for each patient, TreatQuest® asks for demographic information, such as gender, date of birth, diagnosis time, staging information (e.g., tumor size, lymph node, metastasis, and staging code), histology information (e.g., histology code and cancer type). Figure 3-14 illustrates all the patient information collected by TreatQuest®. This information serves two important roles. It describes each patient and the disease. It also functions as the key filters in analytical services, such as accessing the similar cases in public data.

Figure 3-14  Patient Information Collected by TreatQuest®

The patient information is stored in patient table. Figure 3-15 depicts how a fictitious patient is represented by a unique database record.

| | PatientID | DOB | Gender | Age | Race | Race_Recode | YearofBirth | AgeAtDiagnosis | YearOfDiagnosis | MonthOfDiagnosis | AJCC_Stage | AJCC_T | AJCC |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 1 | P1208301655 | 1928-03-09 00:00:00.000 | M | 84 | White | 01 | 1928 | 75 | 2004 | 03 | Stage IV | T2 | N0 |

Figure 3-15  The Tabular Database Representation of Patient

### 3.3.6 Personalized Patient Information

TreatQuest® puts patients at the center of system design and information delivery. Its main goal is to furnish patients with sufficient high-quality information so that they can have greater power, protection, and choice in the key aspects of their healthcare. Practically, patients are also expected to be better prepared for treatment procedures and surgeries after using the system.

TreatQuest® provides both general and specialized information. The general information includes: education material, disease statistics, general questions to the doctor, test procedures, staging information, and frequently asked questions and answers. Specialized information includes similar cases analytical information, standard treatment options based on staging, nomogram and guidelines. This type of information is tailored to the unique situation of each patient. For example, the similar case information will show what treatments the patients with the similar situation in the past have used and how effective they turned out to be.

### 3.3.6.1 Similar Cases Treatment Options

TreatQuest® conducts similar cases search by analyzing large-scale public data. When a patient query is received, the system will retrieve the SEER data using information from the patient profile. Analysis results will be generated and aggregated before sending back to the patient. Specifically, treatment options, total patient count, percentage of patients using the selected treatment and

survival information will be computed and reported. Figure 3-16 is a screenshot of TreatQuest® similar cases analysis based on the SEER data from 2004 to 2006.

**Patient Information**

Gender: Male   Race: White   Age: 70 Age at Diagnosis: 70 Diagnosis Time: 03/2013
AJCC Stage: Stage IIIB TumorSize:   Lymph Node:   Metastasis:   Histology Code:

**Similar Cases and Treatment Used Based on SEER Data diagnosised between 2004-2006**

| In 3 Years Treatment | Patient Count | Percent of Patient Used the Treatment | Percent Alive Use the Treatment | Live Patient Average Survival Months | Percent Death Use the Treatment | Death Patient Average Survival Months | Lung Cancer Cause of Death | Lung Cancer Cause of Death Percent |
|---|---|---|---|---|---|---|---|---|
| Surgery Only | 160 | 19.54% | 30.00% | 37.98 | 70.00% | 12.58 | 92 | 57.50% |
| Radiation Only | 524 | 63.98% | 10.50% | 38.64 | 89.50% | 10.29 | 406 | 77.48% |
| Surgery+Radiation | 112 | 13.68% | 18.75% | 41.24 | 81.25% | 20.79 | 77 | 68.75% |
| Radiation+Surgery | 23 | 2.81% | 30.43% | 46.29 | 69.57% | 21.63 | 13 | 56.52% |
| Total | 819 | 100.00% | 16.00% | 39.22 | 84.00% | 12.31 | 588 | 71.79% |

Figure 3-16 Similar Cases and Treatment Information Given by TreatQuest®

Assume a patient registered with TreatQuest® who has provided information on gender, race, age, and staging, and histology. Based on this profile, patients with similar values on these criteria will be returned. Other than age, all criteria are defined as exact match. The age match is by group instead. For example, patients aged from 70-74 are treated as one group and considered as similar age. For staging information, the query retrieves exactly the same stage. Exact match was also implemented for tumor size, lymph node, metastasis, and histology code. Take tumor size as an example. The possible values for tumor size in the SEER data are T1a, T1b, T2a, T2b, and so on. The similar case inquiries are based on these exact values. For any item that the user didn't give a value in the patient profile, similar case match return all possible cases for that item while filtering them by other criteria available.

Figure 3-16 show the results of a similar case query using the SEER data from 2004 to 2006. The first column in the table lists treatment options that previous patients used. Due to the lack of chemotherapy and other treatment

information in the SEER data, the available treatment options are surgery only, radiation only, surgery then radiation, and radiation then surgery. The second column and third column give the number and percentage of patients receiving each treatment option accordingly. The survival information for the last few columns was based on the three year survival rate.

### 3.3.6.2 Evidence-based Standard Treatment Options by Staging

Evidence-based medicine (EMB) is defined as the best research evidence combined with clinical expertise and the patient's values and preferences to select the appropriate treatment option.  The best research evidence means valid and clinically relevant research, especially from patient-centered clinical research (Straus, 2005[107]). EMB systematically searches a wide range of medical journals by applying strict criteria for the validity of research. This practice of evidence-based medicine requires the application of population-based data to the care of an individual patient (Doi, 2012 [103]). Evidence-based medicine has gradually emerged as integration of the best research evidence with clinical expertise and patient values and preferences and expectations (Eddy, 2005[104]).

In line with EMB, TreatQuest® provides evidence-based information on treatment options by cancer stage, as illustrated in Figure 3-17. This type of information is not only displayed with a list of treatment options but is also supported by evidences from empirical research, clinical expertise, and the clinical trial from NCI website.

Figure 3-17 Standard Treatment Options with Evidence-based Information

### 3.3.6.3 Nomogram for NSCLC Post-Operative Radiotherapy

When first diagnosed with cancer, many patients will ask about their prognosis with questions like "how long can I live?" or "what is the success rate of this treatment option?" Doctors usually give the survival rate based on the location and stage of the tumor. Commonly used statistics include 5-year survival rate and median survival time. For example, a doctor may tell a patient with early stage lung cancer that he or she has a 50% 5-year survival rate.

In general, today's cancer survival rate and median survival time are estimated from a large group of cancer patients. While these estimates do apply to the general population, they are not particularly accurate for individual patients, as they do not include patient-specific information, such as age and disease conditions. While doctors can make adjustments to their survival time prediction

by individual differences, it is more accurate to explicitly incorporate these important factors in the prognostic models. For example, information on tumor size, lymph nodes, and histology reveal important information about the staging of the patient, and therefore will be very useful for predicting how well a patient may respond to a treatment and how long s/he will survive.

The survival prediction tool is designed to help physicians and patients make treatment or surveillance decisions. One such tool, prognostic nomograms, is incorporated into the TreatQuest®. This tool makes individualized estimation of prognosis for non-small cell lung cancer patients. It can help determine whether there will be benefit from a post-operative radiation therapy, or more specifically, whether there is benefit from the radiotherapy.

Consider a 70 years old female patient with a tumor size of T3 (which is smaller than 2 cm from carina, chest wall, diaph) and the nodal status of N1 (ipsilateral pulmonary or hilar lymph nodes). The cancer type is adenocarcinoma. Once the patient selects these options in the system, the prognosis will show these results: predict median survival without radiation therapy as 24 months and median survival with radiation therapy as 25 months. That is to say, the net gain from the post-operative radiation therapy is 1 month. As far as predicted 2-year overall survival, the percentage is 50% without radiation therapy versus 52% with radiation therapy, or a net gain of 2%. With all these results available, the patient can weigh the pros and cons to determine the value of the post-operative radiation therapy to her. Figure 3-18 illustrates this nomogram example.

Non-Small Cell Lung Cancer

**Will you benefit from Post-Operative Radiotherapy?**

Instructions: Enter the details below and the calculator will estimate the benefit of post-operative radiotherapy for you.

Age: 70    Sex: Female / Male

Extent of Primary Tumor:
T1: <3cm
T2: >3cm, bronchus >2cm from carina, visceral pleura, partial atelectasis
T3: <2cm from carina, chest wall, diaph, medias pleura, parietal pericard, complete atelectasis
T4: medias, great vessels, heart, carina, vertebrae, esoph, trachea, 2 in 1 lobe, effusion

Nodal Status:
N0: no positive lymph nodes
N1: ipsi hilar or greater
N2: ipsi mediastinal or subcarinal

Histology:
AdenoCA
Squamous Cell CA
Large Cell CA
Other

Predicted Median Survival: Without RT: 24 months    With RT: 25 months    Net benefit: 1 months

Predicted 2-year Overall Survival: Without RT: 50%    With RT: 52%    Net benefit: 2%

This web calculator is based on a Cox proportional hazards survival model built from a series of non-small cell lung cancer patients from the SEER 17 database.

Figure 3-18  Nomogram for NSCLC Post-Operative Radiotherapy

### 3.3.7 Guidelines in TreatQuest®

According to Wikipedia, a medical guideline is a document with the aim of guiding decisions and criteria regarding diagnosis, management, and treatment in specific areas of healthcare. The term "medical guideline" is synonymous with clinical guideline, clinical protocol, or clinical practice guideline. Medical guidelines have been in use for thousands of years throughout the entire history of medicine. They serve as a guide for doctors to use appropriate methods of treatment and care. They embody the most reliable knowledge base that is produced or endorsed by a national, provincial, or territorial medical or health organization, professional society, government agency, or expert panel. Guidelines can address specific clinical situations (disease-oriented) or use of approved medical products, procedures, or tests (modality-oriented).  Guidelines define the role of specific diagnostic and treatment methods in the diagnosis and management of patients.

Modern clinical practice guidelines identify, summarize, and evaluate the highest quality evidence and most current data on prevention, diagnosis, prognosis, and therapy. They also define the most important questions in clinical practice and identify all possible solutions. They represent summarized consensus statements based on an examination of current evidences within the paradigm of evidence-based medicine.

It has been demonstrated repeatedly that the use of guidelines is an effective way of improving many aspects of healthcare outcome, such as standardizing medical care, raising quality of care, and reducing risk. Although healthcare providers are obliged to know the clinical practice guidelines and use them in treatment, not all clinical practice guidelines have been routinely followed (Gina, 2004[105]). One way to increase the use of the guidelines is to introduce them to the patients so that they can also use that knowledge in their decision making.

### 3.3.7.1 ACCP Guidelines® for Patient (Small Cell Lung Cancer)

The American College of Chest Physicians (ACCP) has provided clinical practice guidelines for many years. Over the last several years, their efforts have been supervised by the ACCP Guidelines Oversight Committee (GOC) to ensure that the guidelines move as closely as possible to an evidence-based platform. Consequently, the guidelines provide the best available evidence-based recommendations for many clinical topics. The ACCP guidelines were incorporated in TreatQuest® as a PDF file. Figure -19 is the screenshot of ACCP Guideline for Small Cell Lung Cancer in TreatQuest®.

Figure 3-19  ACCP Guideline for Small Cell Lung Cancer Screenshot

This ACCP guideline for small cell lung cancer contains information and knowledge from many different aspects. For patients, the most interesting information is the intervention and practices sections, which specifies the routine staging procedure and treatment related information. This guideline also describes the methodology used to collect/select the evidences, such as those based on the systematic review of the literature from peer-reviewed journals. This will help patients understand the major benefits in using clinical practice guidelines.

### 3.3.7.2 NCCN Guidelines for Patients® (Non-Small Cell Lung Cancer)

The National Comprehensive Cancer Network® (NCCN®) recognizes the increasing information needs of patients and has created a patient-friendly version of the NCCN Guidelines, which provides state of the art cancer treatment information in easy-to-understand language. The NCCN Guidelines for Patients®, based on the world-renowned NCCN Clinical Practice Guidelines in Oncology

(NCCN Guidelines®) for cancer care professionals, are meant to help cancer patients and their families better understand cancer and to prepare them to communicate better with physicians on treatment options. Since 2011, The NCCN Guideline for Patients® on Non-Small Cell Lung Cancer has been a very informative educational tool for both physicians and patients.

### 3.3.7.3 NCCN Guidelines for Patient® representation in TreatQuest® (Treatment Wizards for Non-Small Cell Lung Cancer)

Based on the NCCN Guidelines for Patients® of Non-Small Cell Lung Cancer Version 1.2012, different treatment wizards were implemented in TreatQuest®. Based on the stage of non-small cell lung cancer, the guidelines were divided into ten treatment wizards and one test wizard. Depending on the stage of the NSCLC, different treatment process flow will be given to the patient. The process flow is based on test results, health condition, surgery result, and other conditions.

Unlike the paper brochure, the treatment wizards in TreatQuest® are able to provide customized information to patients. Using interactive means to retrieve information and knowledge, the guidelines are presented in a simplified way. More specifically, the Treatment wizards simulate the step by step process flow of a guideline. The wizard-based interface allows the guideline to be implemented as a series of navigation steps.  For each step, ASP.NET wizard control is used to collect user's input and build forms. Based on user's data for the current step, different options are presented for the next step so that the user can choose which direction to go.

An example of how NCCN guideline is represented in TreatQuest® is

described below. Figure 3-20 is a specific NCCN guideline for Stage IV Non-Small cell lung cancer. For this guideline, it is divided into a series of steps. The first step is getting the performance status score of the patient. Based on that score, the second step is to provide information on the first-line treatment. The third step is getting the treatment response for the first-line treatment during first two treatment cycles. Depending on the response, the last step is offering treatment options after the first-line treatment.
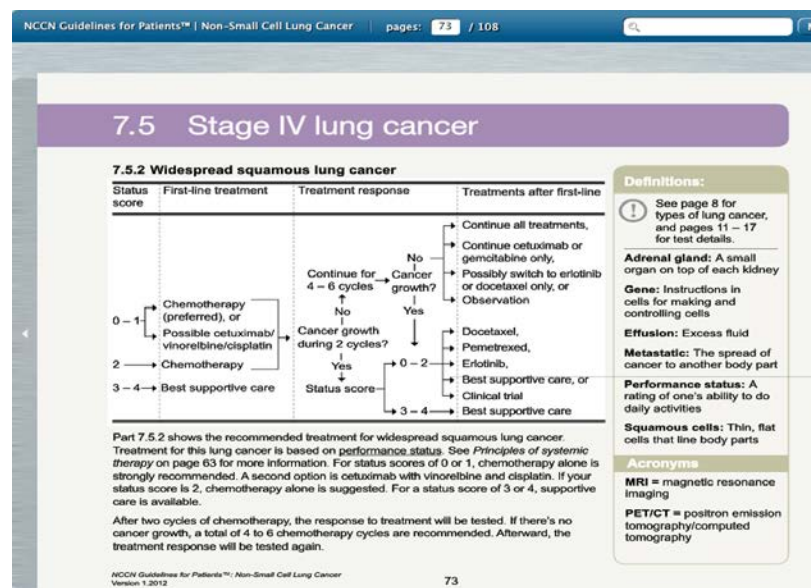


Figure 3-20 Staging IV Widespread Squamous Lung Cancer Guideline example from NCCN Guidelines for Patient of NSLC

How the TreatQuest® treatment wizards actually implements the above guideline is demonstrated below. The guideline rule is specified as: "For Stage IV widespread squamous lung cancer patients, offer chemotherapy as first-line of treatment if the performance status score is 2. Then, if there is no cancer growth during the first two chemotherapy cycles, continue for 4-6 chemotherapy cycles. If there is cancer growth in those chemotherapy cycles, re-evaluate the performance status score. If the score falls between 0 and 2, Docetaxel,

Pemetrexed, Erlotinib, best supportive care, or clinical trial, will be given as the

treatment option after first-line treatment." Figure 3-21 is the screen shot of the

first step in the wizard. Figure 3-22 shows how the patient can obtain more

information on treatment options. Both figures clearly demonstrate how the

guideline is implemented in an interactive mannerin TreatQuest®.



Figure 3-21   Collect performance score using treatment wizard of Stage
IV Non-Small Cell Lung Cancer in TreatQuest®

Figure 3-22   First-line treatment given using treatment wizard of Stage IV Non-Small Cell Lung Cancer in TreatQuest®

### 3.3.8 Customized Search in TreatQuest®

TreatQuest® provides customized search functions to help patients to obtain evidence-based information from major cancer information websites. Using the customized search function, patients can easily retrieve accurate and updated information from major cancer sites right away. By adapting the Google custom search engine, TreatQuest® users can search across a set of credited sites, which are : MedlinePlus website (http://www.nlm.nih.gov/medlineplus/), National Cancer Institute at the National Institutes of Health website (http://www.cancer.gov), National Comprehensive Cancer Network website (http://www.nccn.org),  WebMD website(http://www.webmd.com), US National Library of Medicine's search service PubMed website (http://www.ncbi.nlm.nih.gov/pubmed), and ScienceDirect website(http://www.sciencedirect.com).  The following section will give a brief

introduction of each site and what benefits they bring to TreatQuest®.

**MedlinePlus**

MedlinePlus® is a high-quality gateway to consumer health information from the National Library of Medicine(NLM), the National Institutes of Health (NIH), and other authoritative organizations. MedlinePlus® was rated  by some researchers as the gold-standard web-based consumer health information site (Schloman, 2006 [106]).

MedlinePlus was first released by NLM in 1998. As a government-owned web site, MedlinePlus has offered free service with no advertisements. The site also uses no cookies and requests no personal information. Information at different levels can be requested to meet different needs of patients and families. For example, for users who like to know more research findings, MedlinePlus® integrates PubMed/MEDLINE searching engine for peer-reviewed biomedical journal citations on the Health Topic pages. As another example, for patients coping with a serious or chronic illness, MedlinePlus® can retrieve articles, evidence-based medicine, and consensus practice guidelines. Each MedlinePlus® Health Topic page features a link to the institute with primary research responsibility on certain disease. Users can follow the links to obtain additional information.

**NCI**

The National Cancer Institute (NCI), a component of National Institutes of Health(NIH), is the federal government's principal agency for cancer research and training. The NCI was established under the National Cancer Act of 1937.The Public Health Service Act charged NCI with continuing and expanding programs

to provide physicians and the public with state-of-the-art information about the treatment of individual types of cancer and to identify clinical trials that might benefit patients while advancing knowledge of cancer treatment. The National Cancer Act of 1971 broadened the scope and responsibilities of the NCI and created the National Cancer Program, which supports research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer. The program also provides the supportive care of cancer patients and their families.

The NCI website provides accurate, up-to-date, comprehensive cancer information, hence it is treated as one of the core web sites used by TreatQuest® that help patients acquire cancer information.

**NCCN**

The National Comprehensive Cancer Network (NCCN) is a nonprofit alliance of 21 cancer centers throughout the U.S. Experts from NCCN cancer centers diagnose and treat all cancers, with a particular focus on complex, aggressive, or uncommon cancers. NCCN developed the NCCN Clinical Practice Guidelines in Oncology,  a set of recommendations designed to help health care professionals diagnose, treat, and manage cancer patient care. Additionally, NCCN launched its new series of NCCN Guidelines for Patients™, a consumer-friendly translation of the NCCN Guidelines. The first two guidelines released cover breast and lung cancers.

NCCN's flagship website, NCCN.org, is geared toward health care professionals. It provides them with access to the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®). NCCN.com is the consumer

website that provides the same information as the NCCN.org. Both NCCN websites are included in the core list of web sites used by TreatQuest® so that patients can conduct customized search for high quality cancer treatment information.

**WebMD**

WebMD Health Services provides private health management programs and benefit decision-support portals to employers and health plans. WebMD is primarily known for its public website, which has a huge amount of information on health and health care, such as symptom checklists, pharmacy information, drug information, blogs of physicians with specific topics, and a place to store personal medical information. The WebMD website is a leading health portal in the United States. Since 2001, most WebMD's operations have been accredited by URAC, the largest accrediting body for health care. In addition to the WebMD site itself, the WebMD Health Services also operate other health-related websites, such as MedicineNet, Medscape, eMedicineHealth, and RxList. WebMD is included in the core list of websites that patient can search via TreatQuest®.

**PubMed**

PubMed website is an online retrieval service developed by the National Center for Biotechnology Information (NCBI) at the National Library of Medicine (NLM). PubMed offers free access to MEDLINE, a database of over 10 million bibliographic citations, indexed citations and abstracts to medical, nursing, dental, veterinary, health care, and preclinical sciences journal articles. PubMed also contains links to the full-text versions of articles at participating publishers' web sites, biological data and sequence centers from third parties.

Moreover, PubMed grants access and links to the integrated molecular biology databases maintained by NCBI. Apparently, adding PubMed into the core list of website in TreatQuest® greatly enhances the capacity of users in retrieving research articles.

**ScienceDirect**

ScienceDirect is one of the world's leading sources of scientific, technical, and medical research. It is a full-text database offering articles and book chapters from more than 2,500 peer-reviewed journals and more than 11,000 books. There are currently more than 11 million articles/chapters, a content base that is growing at a rate of almost 0.5 million per year. The ScienceDirect platform offers sophisticated search and retrieval functions that enable users to maximize the effectiveness of their knowledge discovery process. For example, by setting the filter with lung cancer, users can retrieve research papers in this specific area. ScienceDirect is incorporated into TreatQuest®.

# Chapter 4 Evaluation and Results

## 4.1 Introduction

As a discipline, human-computer interaction (HCI) is concerned with the design, evaluation, and implementation of interactive computer systems for humans.  Such systems can be evaluated with respect to many different aspects, for example, functionality, reliability, usability, efficiency, maintainability, and portability. Due to the explosive growth of interactive software in the last decade, usability has gained prominence in system evaluation. Accordingly, our focus in evaluating the TreatQuest® system will be on its usability.

Different definitions of usability have been proposed.  Shackel (Shackel, 1991[107]) defines usability of a system as "the capability in human functional terms to be used easily and effectively by the specified range of users, given specified training and user support, to fulfill the specified range of tasks, with in the specified range of environmental scenarios". One standard definition is provided by the International Organization of Standards (ISO). The ISO 9241-11 standard, also titled Ergonomic requirements for office work with visual display terminals, states that "usability of a product is the extent to which the product can be used by specific users to achieve specific goals with effectiveness, efficiency, and satisfaction in a specific context of use." This definition underlines that for a system to be usable, users should be able to achieve its functions with considerable ease. While the ISO 9241-11 recommendations have become the standard in the usability research, the most widely adopted definition of usability in system evaluation is the one introduced by Nielsen (Nielsen,1993[108]). It provides a detailed model in terms of usability constituents, hence it is more

suitable to be objectively and empirically verified by different evaluation methods. The Nielsen's definition of usability is comprised of the following five components:

1. Learnability: the ease of learning the functionality and the behaviors of the system.

2. Efficiency: the level of attainable productivity once a user has learned the system.

3. Memorability: the ease of remembering the system functionality. This refers to how easily a casual user can return to the system after a period of non-use.

4. Few errors: the capability of the system to feature a low error rate, to support users making fewer errors in using the system, and in case an error is made, to help them to recover easily.

5. User satisfaction: the level users find the system pleasant to use.

## 4.2 Evaluation Methods

The usability of a system can be evaluated by multiple techniques and methods. Three types of usability evaluation methods are empirical method, inspection method, and inquiry method. The empirical method is user-oriented. It is based on the systematic evaluation of users' experience with a system. The inspection method, on the other hand, is specialist-oriented. A specialist, such as a software developer, can examine the usability-related aspects of a user interface. The inquiry method focuses on the interaction between users and professionals. A specialist may ask a user how he or she likes, dislikes, and understands the system by oral and written communication. A specialist may also

observe how a user actually uses the system in real work. Table 4-1 summarizes the methods used by the above three evaluation categories.

Table 4-1   Usability Evaluation Methods

| Method Category | Methods |
|---|---|
| Inquiry Method | o User satisfaction questionnaire<br>o Field observation<br>o Focus group<br>o Interviews |
| Empirical Method | o Thinking aloud method<br>o User performance test<br>o Remote usability test<br>o Beta test<br>o Forum test<br>o Cooperative evaluation<br>o Coaching method |
| Inspection Method | o Expert review<br>o Heuristic evaluation<br>o Cognitive walkthrough<br>o Pluralistic walkthrough<br>o Structured heuristic evaluation<br>o Perspective-based inspection |

Since the inquiry method tends to identify broad usability problems and to seek opinions about the systems as a whole, it was used in evaluating the TreatQuest® system. In applying this method, a web-based user satisfaction questionnaire was developed to seek the feedback from patients. Field observation was also conducted to evaluate the system.

**4.3 Determining the Number of Users to Test**

While the common wisdom may favor a large number of users to test the system, Nielsen has argued against that approach, as to him, elaborate usability tests is too costly and acceptable results can be achieved from as few as 5 users (Jackob,1993 [109]). A mathematical model has been established for computing the exact number of users in usability tests (Jackob and Landauer, 1993 [110]).

The model is

$$K = N(1-(1-\lambda)^i) \qquad\qquad (EQ4.1)$$

where N is the number of questions to be evaluated, $\lambda$ is the probability that one

subject is able to find the average problem, and i is the number of test subjects.

This model can also be illustrated by curves over a common range of $\lambda$ values, as

in Figure 4-1.
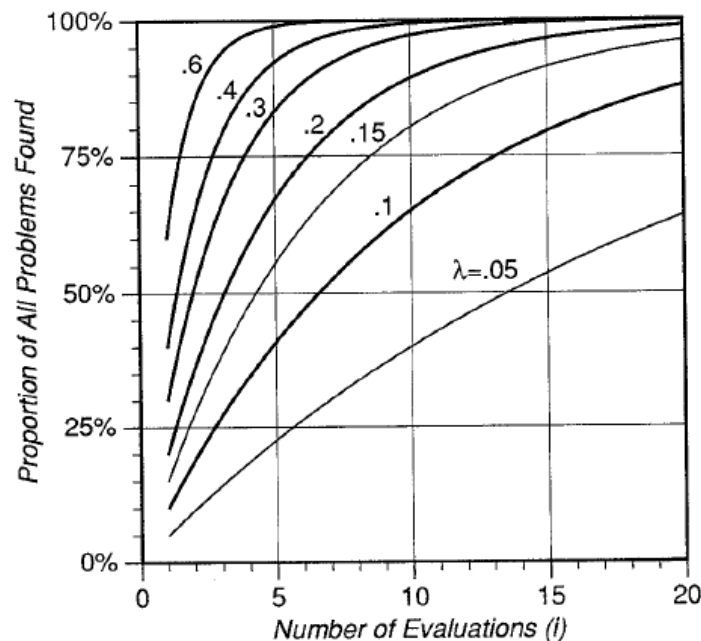


Figure 4-1  Relationship between Number of Test Users and Proportion of Usability Problems Found

Based on a large number of experiments, Nielsen (Nielsen, 1993 [111])

pointed out that the average proportion of usability problems discovered by a

single user is about 31%. Using that as the estimate of the $\lambda$ value in the figure,

we would need about 15 users to discover all the usability problems. These 15

users could be selected by two steps: the first 5 users to identify the initial

problems in the design and the next 10 users to validate the identified problems

and to look for new ones.

### 4.4 Data Analysis and Result

### 4.4.1 Data Collection

The data for evaluating TreatQuest® was collected from lung cancer patients who have used the system. The newly diagnosed lung cancer patients from Columbia St. Mary's Cancer Center in Milwaukee were contacted to participate in the study.

Once a patient filled out the consent form, a training session was arranged to help the patient familiar with the TreatQuest® system. The training provided an overview of the system, demonstrated how to use the system, and finally helped the patient to setup an account and to create profile in the TreatQuest® system. Meanwhile, the nurse coordinator from the at Columbia St. Mary's Cancer Center helped the patient to prepare a disease profile in the TreatQuest®. Once the patient or their family member had an account with TreatQuest® system, they could start to use the system. After using the TreatQuest® for a period of time (e.g., a month), the patient would be asked to fill out a survey to evaluate the system.

### 4.4.2 Observation during Training

At each training session, I observed how the patient and their family members interacted with the TreatQuest® system. Their comments on the general features as well as specific functions were recorded and analyzed. Table 4-3 provides some observation during training session.

In general, patient and/or their family members were interested in the value that TreatQuest offers. They indicated that the system was easy to use and

not hard to navigate and find information. No patient or family members considered themselves as computer savvy, but they expressed that the system was user-friendly.

### 4.4.3 Survey and Survey Data

The main goals in evaluating the TreatQuest® system were to conclude how well the prototype system actually performs and also to explore how the users like the system. To achieve that, both qualitative and quantitative data were collected. The quantitative data came from the numerical rating in answering the likert-scale questions on an online patient survey. The qualitative data, on the other hand, were based on the narratives that users provided in answering short-answer questions. These answers helped to delve into more depth of user satisfaction.

A patient survey was conducted to identify whether the system has achieved its goals, what problems users still encounter, and what recommendations users have for improving the systems. By adapting the afore-mentioned Nielsen's definition of usability to a decision support system like TreatQuest®, the survey covered the following 6 areas: ease of use, learnability, information facilitation (i.e., how quickly patients can locate information), look and feel consistency (e.g., how the pages look and feel), content of the site (e.g., whether the content will keep patients coming back), and finally, site organization.

As shown in Appendix I, the whole survey has 40 items which were arranged in three parts. The first part asks for demographic information, such as education level and attitude towards Internet use for healthcare system. The second part consists of questions on specific TreatQuest® functions such as

treatment wizard and search. The final part asks questions on the overall impression of the system, such as how easy it is to use and navigation the system.

Survey questions were written in the format of Likert scale. Participants were asked to indicate the degree of agreement with the statement on a five point agreement scale. These statements had been carefully selected to measure users' perception and attitudes toward the benefit of using the TreatQuest®. Figure 4-2 gives an exemplary item. Short-answer questions were also included in the survey to collect more open-ended response on some aspects of the system.

| | Strongly Agree | Agree | Uncertain | Disagree | Strongly Disagree |
|---|---|---|---|---|---|
| 30. TreatQuest website is easy to use. | ○ | ○ | ○ | ○ | ○ |
| | ○ | ○ | ○ | ○ | ○ |

Figure 4-2  Survey Question Example

In practice, a patient was first introduced to the system by the developer. Then the patient filled out a survey to indicate the satisfaction level after using the system for a period of time (eg. a month). As discussed above, their answer to the 40 items on the survey provided plentiful data on the core functions of the system, such as access to knowledge resources, decision support, as well as usability, such as intent to use and user satisfaction.

### 4.4.4 Preliminary Evaluation Results

Altogether seven patients completed the evaluation study. Their demographic information was in Table 4-2. While a small sample, they did represent quite a diverse group. As shown in the table, they represented different genders, races, age groups, and stages. Two patients are female, the others

patients are male.  The races of the patient included both white and black. The age

of those patients range from 54 to 79.

Table 4-2 Characteristics of Patient Samples

| Characteristic | Number of Patients (Percentage of Patients) |
|---|---|
| Gender | |
| Male | 5 (71%) |
| Female | 2 (29%) |
| Age Group | |
| 50-54 | 1 (14%) |
| 55-59 | 1 (14%) |
| 60-64 | 2 (29%) |
| 65-69 | 2 (29%) |
| 70-74 | |
| 75-79 | 1 (14%) |
| Race/ethnicity | |
| White | 6 (86%) |
| Black | 1 (14%) |
| Stage at Diagnosis | |
| Stage II | 1 (14%) |
| Stage III | 2 (29%) |
| Stage IV | 4 (57%) |

**4.4.4.1 Field Observation Results**

In general, the feedback has been extremely positive. Most patients

indicated that TreatQuest® website was clear, straightforward, and easy to find

the treatment-related information. More importantly, patients were enthusiastic

about the value TreatQuest® provides to them. For example, at the end of one

training session, one couple commented: "Thank you very much to put together

such valuable system to provide valuable source of information and knowledge.

We are certainly looking for second opinion and want to learn more information

and knowledge."  Table 4-3 complies the users' comments by topic.

Table 4-3 User's Comments

| |
|---|
| On Education Materials: <br><br> o This information is very helpful. Can you print this for me now? Some of those questions are exactly what we want answered. <br><br> o I want to check with the nurse to see if they have any brochure like this. <br><br> o It is always nice to have the glossary of terms. You might want to know the meaning of some terms. |
| On Treatment Wizards: <br><br> o I think this will add to our knowledge. I'll check whether my husband had done tests listed here. <br><br> o The information about the surgery type in the wizard is useful. |
| On Similar Cases and Treatment Used <br><br> o It is good to have similar cases information although chemotherapy and target therapy information are not available <br><br> o Physician is considering surgery; the information about the surgery type is good to have. |
| On Treatment Options and Evidences: <br><br> o A lot of information presented here. I have to find time to go through. <br><br> o Let's skip the statistics numbers |
| On Nomogram <br><br> o Which histology I should choose? What is the net benefit? |
| From FAQs <br><br> o It is convenient to have FAQs. |
| On Search function <br><br> o It is neat to have the search function and integrate all those information together. |

## 4.4.4.2 On-line Survey Results

Out of the seven patients who received the training of the TreatQuest® system, five provided survey responses. Regarding their background, four received higher education. All of them indicated that they were frequent internet users. About 60% of them indicated that they did use internet to search for health or medical information. They all expressed that they felt comfortable to use information from internet to communicate with their physicians. Along with that, they all agreed that the external information could help them to make health/treatment related decisions. With regard to the information provided by their physicians, while some thought it was enough, others were looking for a second opinion.

Regarding the information provided by the TreatQuest® system, their response varied by topic. All patients agreed that education material in MyTreatQuest was informative and could potentially help them to communicate with a physician. They either agreed or strongly agreed with the statements that Treatment Wizard can provide a helpful guide, clear explanation and information that they are looking for and treatment wizard is helpful in discussing my treatment options with a physician. For information presented to patients, they indicated that similar cases and treatment used based SEER data were informative and would help them in making treatment decisions or communicating with their physicians.

All patients were satisfied with the information provided from the "Your Treatment Options and Evidences Based on NCI" part. However, some patients were uncertain about Nomogram functions. Also, surprisingly, not all patients

were in favor of the statistics information provided by the TreatQuest®. Some of them tried to skip that during the training session. But both the Frequently Asked Questions and Questions to Ask My Doctor sections were deemed informative to all patients.

In general, patients found the TreatQuest® website easy to use and navigate. All patients agreed that the content is well organized, and website gives a consistent look and feel. Most of the patients (80%) agreed that the TreatQuest® website contains mostly the treatment related information that they are interested in and it also provides evidence-based information to help them make treatment decisions. Eighty percent patients indicated that they were very likely to recommend the website to other patients in the future.

In the survey responses, some patients also listed other website they were using to find lung cancer-related information. One example is the www.MayoClinic.com.  Some patient suggested adding diagnosis related information to TreatQuest® website. As far as the information that most affected their treatment decision, some chose side effects; some chose to prolong the overall survival; the majority chose doctor's opinion.

Overall, the survey results show that TreatQuest® performed well to offer evidence-related information to patients, and could play an important role in helping patients to make treatment-related decisions. The complete survey results can be seen in Appendix F.

### 4.5 Physician Inputs and Opinions

During the phase of design and testing of the TreatQuest® system, the physicians and nurses of Columbia and St. Mary's hospital not only verified the

system but also offered valuable suggestions on how to further improve the system. Examples of those suggestions were:

- limit the histology code so that it is simple to use when patients enter their profile information
- add illustrative pictures to the treatment wizard for different stages so that users have a better idea of what "stage" means
- add more detailed specification on the origin of clinical trials, add the glossary of term and
- remove the cancer risk calculator as patients have already been diagnosed with lung cancer.

All these suggestions have been implemented on TreatQuest® and the system has become more user-friendly.

All physicians and nurses from Columbia St. Mary's hospital involved with this study were in favor of the system. They also shared the latest research information in this area with the researchers. To them, TreatQuest® system is valuable to lung cancer patients due to its ability to help patients better understand treatment options, thus more ready to make a collaborative medical decision.

# Chapter 5 Discussion

## 5.1 Conclusion

According to a recent Pew Internet & American Life report Project (Fox and Duggan, 2013[112]), 59% of U.S. adults indicated that they had looked for health information online in the past year and 35% had gone online specifically for figuring out the medical condition they or someone else might have. The report also found that the health information seekers were action-oriented and highly purposeful. These finding are somewhat surprising as most of these people have already received information from their physicians and healthcare givers. It is noticeable that patients and their family members join the stream of information pathway. One way to help these consumers is practicing consumer-centered health informatics.

As a relatively young field, consumer health informatics has the potential to provide frameworks and strategies for designing effective health communication tools that empower users and improve their health decisions (Keselman et al., 2008[113]). It provides services in patient-focused informatics, health literacy, and consumer education.  It is devoted to informatics from the consumer or patient perspective. This new approach requires us to analyze consumers' needs for information, study and implement methods for making information accessible to consumers, and model and integrate consumers' preferences into health information systems.

This dissertation advanced the consumer informatics field by contributing one solution, the TreatQuest® system. The overall goal in designing this patient

decision support system was to improve the quality of decision making for patients. This has been achieved by using evidence-based knowledge and large-scale data and building in inquiry functions to provide patient-tailored information. As a web application, the system is always available to patients. By following the software development cycle and web design principles, the system is stable and highly user-friendly. Using this system, patients can generate in-depth insights into the decision process. They can educate themselves about the disease, compare different treatment options and their outcomes, and study the implications of their preferred treatment. Hopefully, a DSS like this will play a key role in the decision process of many patients.

This dissertation research provides many insights on how to design an effective patient decision support system. The prototype was set up to help lung cancer patients to access evidence-based information and knowledge. The design can be easily applied to develop systems focused on other diseases. The key components for the systems include high-quality large-scale data source and analytic tools, industry guidelines and other knowledge bases, interactive search functions, user friendly interfaces, and web application. When these components are synthesized into a system, patients have a reliable resource to seek high-quality information. The system evaluation results show that the use of TreatQuest® can actually help patients obtain the targeted information and enhance communication with physicians to achieve shared decision making.

## 5.2 Limitations of the Study

Several limitations exist for the current study. First, treatment information is limited to what is available from the SEER data. As commented by patients in

the evaluation study, no chemotherapy and target therapy information are included in the system, hence users will not be able to look for similar cases along those lines, which are actually quite standard treatments.  Second, so far, TreatQuest® does not have the capacity to support all browsers as the system was built using the Microsoft technology. As the attention has been mainly on how to build an efficient and stable system, compatibility has not been given enough care. While most functions are supported in most browsers, there are functions that do not work as designed in some browsers. Third, the sample size for system evaluation is small. While tremendous effort has been put into recruiting by me and my advisor, and the hospital had been very cooperative, the data collection has taken much longer than expected, the sample size was still quite small, maybe due to the following reasons. First, the number of lung cancer patients a hospital treats is limited. Second, many patients are not willing to participate in a research study, which is understandable, considering their health status. Even for those who participated, not all of them return the survey results. The small number of responses limits our ability to draw any significant conclusions. Though they did provide many insightful, usually positive, comments about the usability of the system, no usability or performance problems were identified.

Newly diagnosed older lung cancer patients who have lived into later years of life may have concurrent ailments (e. g, diabetes, chronic obstructive pulmonary disease, heart disease, arthritis, and hypertension). In other words, they usually have multiple health problems.  Those comorbidities could affect treatment choice, prognosis, and survival since comorbidity has an important impact and greatly increases the complexity of

managing disease in patients. TreatQuest® will not able to give all guidelines and treatment information for those complicated cases. The guidelines given by the system will not address how other comorbidities may influence the treatment decisions and the cancer course either.

### 5.3 Future Directions

The first direction is to extend the prototype to other types of cancer. While lung cancer is the most popular cancer, patients of other types of cancer need as much help. One critical step in the extension is to locate the high-quality data source, such as the SEER-Medicare data. In addition, industrial guidelines are also helpful. The other important aspect is to understand the needs of patients.

One feature that can be expanded is the survival prediction function. The current system took advantage of a module to conduct survival prediction analysis. Future research can work on building a more customized survival model based on the population data.

Another direction for future research is to extend the system to mobile devices. One important feature of a decision support system like TreatQuest® is it is available all the time. Though mobile devices have been adopted to deliver many health services (Wu et al., 2005 [114]), how suitable they are for a patient decision support system is unclear and asks for further study. This direction can also include to expand the social networking features in the system. Social networking technology is shaping how people and organizations interact and share information. Studies can be designed to understand how social networking impacts patient decision making as well as how to integrate social networking in the decision support system.

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# Appendices

## Appendix A: SEER Data Dictionary

SEER RESEARCH DATA RECORD DESCRIPTION

CASES DIAGNOSED IN 1973-2008*

Submission: *November 2010*

Follow-up Cutoff Date: *December 31, 2008*

Documentation Version: *October 2011*

Diagnosis Years: *1973-2008*

* This documentation describes the data files in the incidence/yr1973_2008.seer9,
yr1992_2008.sj_la_rg_ak, yr2000_2008.ca_ky_lo_nj , and yr2005.lo_2nd_half directories. Refer to
individual variable definitions to determine the differences between the directory files.

Cervix in situ cases after 1995 are not included.

| Item Name | Applicable Years | NAACCR Item # | Positions | Length |
|---|---|---|---|---|
| Patient ID number | | 20 | 1-8 | 8 |
| Registry ID | | 40 | 9-18 | 10 |
| Marital Status at DX | | 150 | 19-19 | 1 |
| Race/Ethnicity | | 160 | 20-21 | 2 |
| Spanish/Hispanic Origin | | 190 | 22-22 | 1 |
| NHIA Derived Hispanic Origin | | 191 | 23-23 | 1 |
| Sex | | 220 | 24-24 | 1 |
| Age at diagnosis | | 230 | 25-27 | 3 |
| Year of Birth | | 240 | 28-31 | 4 |
| Birth Place | | 250 | 32-34 | 3 |
| Sequence Number--Central | | 380 | 35-36 | 2 |
| Month of diagnosis | | 390 | 37-38 | 2 |
| Year of diagnosis | | 390 | 39-42 | 4 |
| Primary Site | | 400 | 43-46 | 4 |
| Laterality | | 410 | 47-47 | 1 |
| Histology (92-00) ICD-O-2 | | 420 | 48-51 | 4 |
| Behavior (92-00) ICD-O-2 | | 430 | 52-52 | 1 |
| Histologic Type ICD-O-3 | | 522 | 53-56 | 4 |
| Behavior Code ICD-O-3 | | 523 | 57-57 | 1 |
| Grade | | 440 | 58-58 | 1 |
| Diagnostic Confirmation | | 490 | 59-59 | 1 |
| Type of Reporting Source | | 500 | 60-60 | 1 |
| EOD—Tumor Size | 1988-2003 | 780 | 61-63 | 3 |
| EOD—Extension | 1988-2003 | 790 | 64-65 | 2 |
| EOD—Extension Prost Path | 1985-2003 | 800 | 66-67 | 2 |
| EOD—Lymph Node Involv | 1988-2003 | 810 | 68-68 | 1 |
| Regional Nodes Positive | 1988+ | 820 | 69-70 | 2 |
| Regional Nodes Examined | 1988+ | 830 | 71-72 | 2 |
| EOD—Old 13 Digit | 1973-1982 | 840 | 73-85 | 13 |
| EOD—Old 2 Digit | 1973-1982 | 850 | 86-87 | 2 |
| EOD—Old 4 Digit | 1983-1987 | 860 | 88-91 | 4 |
| Coding System for EOD | 1973-2003 | 870 | 92-92 | 1 |
| Tumor Marker 1 | 1990-2003 | 1150 | 93-93 | 1 |
| Tumor Marker 2 | 1990-2003 | 1160 | 94-94 | 1 |
| Tumor Marker 3 | 1998-2003 | 1170 | 95-95 | 1 |
| CS Tumor Size | 2004+ | 2800 | 96-98 | 3 |
| CS Extension | 2004+ | 2810 | 99-101 | 3 |
| CS Lymph Nodes | 2004+ | 2830 | 102-104 | 3 |
| CS Mets at Dx | 2004+ | 2850 | 105-106 | 2 |
| CS Site-Specific Factor 1 | 2004+ | 2880 | 107-109 | 3 |
| CS Site-Specific Factor 2 | 2004+ | 2890 | 110-112 | 3 |

| Item Name | Applicable Years | NAACCR Item # | Positions | Length |
|---|---|---|---|---|
| CS Site-Specific Factor 3 | 2004+ | 2900 | 113-115 | 3 |
| CS Site-Specific Factor 4 | 2004+ | 2910 | 116-118 | 3 |
| CS Site-Specific Factor 5 | 2004+ | 2920 | 119-121 | 3 |
| CS Site-Specific Factor 6 | 2004+ | 2930 | 122-124 | 3 |
| CS Site-Specific Factor 25 | 2004+ | 2879 | 125-127 | 3 |
| Derived AJCC T | 2004+ | 2940 | 128-129 | 2 |
| Derived AJCC N | 2004+ | 2960 | 130-131 | 2 |
| Derived AJCC M | 2004+ | 2980 | 132-133 | 2 |
| Derived AJCC Stage Group | 2004+ | 3000 | 134-135 | 2 |
| Derived SS1977 | 2004+ | 3010 | 136-136 | 1 |
| Derived SS2000 | 2004+ | 3020 | 137-137 | 1 |
| Derived AJCC—Flag | 2004+ | 3030 | 138-138 | 1 |
| Derived SS1977—Flag | 2004+ | 3040 | 139-139 | 1 |
| Derived SS2000—Flag | 2004+ | 3050 | 140-140 | 1 |
| CS Version Input Original | 2004+ | 2935 | 141-146 | 6 |
| CS Version Derived | 2004+ | 2936 | 147-152 | 6 |
| CS Version Input Current | 2004+ | 2937 | 153-158 | 6 |
| RX Summ—Surg Prim Site | 1998+ | 1290 | 159-160 | 2 |
| RX Summ—Scope Reg LN Sur | 2003+ | 1292 | 161-161 | 1 |
| RX Summ—Surg Oth Reg/Dis | 2003+ | 1294 | 162-162 | 1 |
| RX Summ—Reg LN Examined | 1998-2002 | 1296 | 163-164 | 2 |
| RX Summ—Reconstruct 1st | 1998-2002 | 1330 | 165-165 | 1 |
| Reason for no surgery | | 1340 | 166-166 | 1 |
| RX Summ—Radiation | | 1360 | 167-167 | 1 |
| RX Summ—Rad to CNS | 1988-1997 | 1370 | 168-168 | 1 |
| RX Summ—Surg / Rad Seq | | 1380 | 169-169 | 1 |
| RX Summ—Surgery Type | 1973-1997 | 1640 | 170-171 | 2 |
| RX Summ—Surg Site 98-02 | 1998-2002 | 1646 | 172-173 | 2 |
| RX Summ—Scope Reg 98-02 | 1998-2002 | 1647 | 174-174 | 1 |
| RX Summ—Surg Oth 98-02 | 1998-2002 | 1648 | 175-175 | 1 |
| SEER Record Number | | 2190 | 176-177 | 2 |
| Over-ride age/site/morph | | 1990 | 178-178 | 1 |
| Over-ride seqno/dxconf | | 2000 | 179-179 | 1 |
| Over-ride site/lat/seqno | | 2010 | 180-180 | 1 |
| Over-ride surg/dxconf | | 2020 | 181-181 | 1 |
| Over-ride site/type | | 2030 | 182-182 | 1 |
| Over-ride histology | | 2040 | 183-183 | 1 |
| Over-ride report source | | 2050 | 184-184 | 1 |
| Over-ride ill-define site | | 2060 | 185-185 | 1 |
| Over-ride Leuk, Lymph | | 2070 | 186-186 | 1 |
| Over-ride site/behavior | | 2071 | 187-187 | 1 |
| Over-ride site/eod/dx dt | | 2072 | 188-188 | 1 |

| Item Name | Applicable Years | NAACCR Item # | Positions | Length |
|---|---|---|---|---|
| Over-ride site/lat/eod | | 2073 | 189-189 | 1 |
| Over-ride site/lat/morph | | 2074 | 190-190 | 1 |
| SEER Type of Follow-up | | 2180 | 191-191 | 1 |
| Age Recode <1 Year olds | | N/A | 192-193 | 2 |
| Site Recode | | N/A | 194-198 | 5 |
| Site Rec with Kaposi and Mesothelioma | | N/A | 199-203 | 5 |
| Recode ICD-O-2 to 9 | | N/A | 204-207 | 4 |
| Recode ICD-O-2 to 10 | | N/A | 208-211 | 4 |
| ICCC site recode ICD-O-2 | | N/A | 212-214 | 3 |
| SEER modified ICCC site recode ICD-O-2 | | N/A | 215-217 | 3 |
| ICCC site recode ICD-O-3 | | N/A | 218-220 | 3 |
| ICCC site recode extended ICD-O-3 | | N/A | 221-223 | 3 |
| Behavior Recode for Analysis | | N/A | 224-224 | 1 |
| ICD-O Coding Scheme | | N/A | 225-225 | 1 |
| Histology Recode—Broad Groupings | | N/A | 226-227 | 2 |
| Histology Recode—Brain Groupings | | N/A | 228-229 | 2 |
| CS Schema v0202 | | N/A | 230-232 | 3 |
| Race recode (White, Black, Other) | | N/A | 233-233 | 1 |
| Race recode (W, B, AI, API) | | N/A | 234-234 | 1 |
| Origin recode NHIA (Hispanic, Non-Hisp) | | N/A | 235-235 | 1 |
| SEER historic stage A | | N/A | 236-236 | 1 |
| AJCC stage 3rd edition (1988-2003) | | N/A | 237-238 | 2 |
| SEER modified AJCC Stage 3rd ed (1988-2003) | | N/A | 239-240 | 2 |
| SEER Summary Stage 1977 (1995-2000) | 1995-2000 | N/A | 241-241 | 1 |
| SEER Summary Stage 2000 (2001-2003) | 2001-2003 | N/A | 242-242 | 1 |
| Number of primaries | | N/A | 243-244 | 2 |
| First malignant primary indicator | | N/A | 245-245 | 1 |
| State-county recode | | N/A | 246-250 | 5 |
| Survival time recode | | N/A | 251-254 | 4 |
| Cause of Death to SEER site recode | | N/A | 255-259 | 5 |
| COD to site rec KM | | N/A | 260-264 | 5 |
| Vital Status recode | | N/A | 265-265 | 1 |
| IHS Link | | 192 | 266-266 | 1 |
| Summary stage 2000 (1998+) | 1998+ | N/A | 267-267 | 1 |
| AYA site recode | | N/A | 268-269 | 2 |
| Lymphoma subtype recode | | N/A | 270-271 | 2 |
| SEER Cause-Specific Death Classification | | N/A | 272-272 | 1 |
| SEER Other Cause of Death Classification | | N/A | 273-273 | 1 |
| CS Tumor Size/Ext Eval | 2004+ | 2820 | 274-274 | 1 |
| CS Lymph Nodes Eval | 2004+ | 2840 | 275-275 | 1 |
| CS Mets Eval | 2004+ | 2860 | 276-276 | 1 |

# Appendix B: SEER Data Usage Agreement

Last Name: HU
SEER ID: 12841-Nov2010
Request Type: Internet Access

**SURVEILLANCE, EPIDEMIOLOGY, AND END RESULTS PROGRAM**
Data-Use Agreement for the 1973-2008 SEER Research Data File

It is of utmost importance to protect the identities of cancer patients. Every effort has been made to exclude identifying information on individual patients from the computer files. Certain demographic information - such as sex, race, etc. - has been included for research purposes. All research results must be presented or published in a manner that ensures that no individual can be identified. In addition, there must be no attempt either to identify individuals from any computer file or to link with a computer file containing patient identifiers.

In order for the Surveillance, Epidemiology, and End Results Program to provide access to its Research Data File to you, it is necessary that you agree to the following provisions.

1. I will not use - or permit others to use - the data in any way other than for statistical reporting and analysis for research purposes. I must notify the SEER Program if I discover that there has been any other use of the data.

2. I will not present or publish data in which an individual patient can be identified. I will not publish any information on an individual patient, including any information generated on an individual case by the case listing session of SEER*Stat. In addition, I will avoid publication of statistics for very small groups.

3. I will not attempt either to link - or permit others to link - the data with individually identified records in another database.

4. I will not attempt to learn the identity of any patient whose cancer data is contained in the supplied file(s).

5. If I inadvertently discover the identity of any patient, then (a) I will make no use of this knowledge, (b) I will notify the SEER Program of the incident, and (c) I will inform no one else of the discovered identity.

6. I will not either release - or permit others to release - the data - in full or in part - to any person except with the written approval of the SEER Program. In particular, all members of a research team who have access to the data must sign this data-use agreement.

7. I will use appropriate safeguards to prevent use or disclosure of the information other than as provided for by this data-use agreement. If accessing the data from a centralized location on a time sharing computer system or LAN with SEER*Stat or another statistical package, I will not share my logon name or password with any other individuals. I will also not allow any other individuals to use my computer account after I have logged on with my logon name and password.

8. For all software provided by the SEER Program, I will not copy it, distribute it, reverse engineer it, profit from its sale or use, or incorporate it in any other software system.

9. I will cite the source of information in all publications. The appropriate citation is associated with the data file used. (Please see either Suggested Citations on the SEER*Stat Help menu or the Readme.txt associated with the ASCII text version of the SEER data (CD #2).)

My signature indicates that I agree to comply with the above stated provisions.

Signature

DATE                                    Date

Please print, sign, and date the agreement. Send the form to The SEER Program:

- By fax to 301-628-1293
- Or, e-mail a scanned form to seerfax@imsweb.com

# Appendix C: UWM IRB Approval

**UNIVERSITY of WISCONSIN**

## UWMILWAUKEE

**Department of University Safety & Assurances**

Melissa Spadanuda
*IRB Manager*
*Institutional Review Board*
Engelmann 270
P. O. Box 413
Milwaukee, WI 53201-0413
(414) 229-3173 *phone*
(414) 229-6729 *fax*

http://www.irb.uwm.edu
spadanud@uwm.edu

### New Study - Notice of IRB Expedited Approval

**Date:** December 3, 2012

**To:** Hemant Jain, PhD
**Dept:** Lubar School of Business

**Cc:** Danqing Hu

**IRB#:** 13.183
**Title:** Patient-Oriented Evidence-Based Treatment Decision Support System (TreatQuest) for Lung Cancer

After review of your research protocol by the University of Wisconsin – Milwaukee Institutional Review Board, your protocol has been approved as minimal risk Expedited under Category 7 as governed by 45 CFR 46.110.

The Institutional Review Board has also granted approval to access protected health information for the purpose of this study which includes:

- Self reported health information about lung cancer diagnosis

This protocol has been approved on December 3, 2012 for one year. IRB approval will expire on December 2, 2013. If you plan to continue any research related activities (e.g., enrollment of subjects, study interventions, data analysis, etc.) past the date of IRB expiration, a continuation for IRB approval must be filed by the submission deadline. If the study is closed or completed before the IRB expiration date, please notify the IRB by completing and submitting the Continuing Review form found on the IRB website.

Unless specifically where the change is necessary to eliminate apparent immediate hazards to the subjects, any proposed changes to the protocol must be reviewed by the IRB before implementation. It is the principal investigator's responsibility to adhere to the policies and guidelines set forth by the UWM IRB and maintain proper documentation of its records and promptly report to the IRB any adverse events which require reporting.

It is the principal investigator's responsibility to adhere to UWM and UW System Policies, and any applicable state and federal laws governing activities the principal investigator may seek to employ (e.g., FERPA, Radiation Safety, UWM Data Security, UW System policy on Prizes, Awards and Gifts, state gambling laws, etc.) which are independent of IRB review/approval.

Contact the IRB office if you have any further questions. Thank you for your cooperation and best wishes for a successful project

Respectfully,

Melissa C. Spadanuda
IRB Manager

# Appendix D: CSM Operational Approval Memo

**Columbia St. Mary's**
*A Passion for Patient Care*

Date: December 20, 2012
To: Hemant Jain, PhD
Danqing Hu, Student Researcher
Varsha Shah, MD, Principal Investigator
Kathy Brown, RN, Research Coordinator
Julie Hugg, Research Coordinator
From: Diana Lenhardt, Manager, Research
Re: **Operational Approval – TreatQuest**

This memo serves as notification of operational approval for the study entitled, *"Patient Oriented Evidence Based Decision Support System (TreatQuest) for Lung Cancer."* This study received CSM IRB approval on December 3, 2012 and CSM operational approval on December 20, 2012. This study is now ready for patient enrollment at Columbia St. Mary's Water Tower Medical Commons.

I have listed a few items below to serve as reminders to all involved in the study. Please call me if you have any questions. Thank you.

| Topic | Task |
|---|---|
| Roles/Responsibilities of all Involved | Dr. Hemant Jain is the Principal Investigator for this study and is responsible for the overall conduct of the study. Dr. Varsha Shah is the CSM Host Investigator for this study who will assist in identifying eligible patients for study, and consent patients if time permits. Danqing Hu is the Student Research Coordinator responsible for consenting, meeting and training patients on the TreatQuest system. Kathy Brown is the back up Research Coordinator to assist with consenting, training, and supplying medical record/staging information. |
| Patient Identification | Dr. Shah to speak with eligible patients about the study. If interested, Dr. Shah (or Kathy as backup) can consent patient to study and provide them with TreatQuest training and the computer link. If the patient is unsure about the study, Dr. Shah to provide the two study letters to the patient for review. The patient can then follow up with Dr. Jain or Danqing if they are interested in the study.

Kathy to notify Danqing of any consented patients and provide the signed informed consent document and HIPAA Authorization to Danqing.

Kathy to notify Danqing of upcoming potential patients for the study. Danqing can come to the Cancer Clinic when the patients come for their visit. If the patient is interested in the study, Danqing can consent the patient to the study and provide TreatQuest training. Kathy to provide study information to Drs. Keefe and Tiber in order for |

| Topic | Task |
|---|---|
| | them to help identify prospective patients to study.<br><br>Only patients who have not started treatment are eligible for the study. |
| **Consenting** | Dr. Shah, Danqing Hu, and Kathy Brown are the only ones approved to consent patients to study.<br><br>The Research Informed Consent and the HIPAA Authorization for research to be signed and dated by patient and person obtaining consent. A copy of both signed and dated forms to be given to the patient, put in the patient's medical record, and kept with Danqing in the study records. |
| **Medical Record Documentation** | All documents in medical record:<br>• Copy of the IRB approved informed consent, signed and dated by the subject<br>• Copy of the Research HIPAA Authorization, signed and dated by the subject |
| **Subject Records** | Danqing Hu to house research patient records separately from the clinic medical record. The research records to be stored in a locked, secure location. |
| **IRB Requirements** | All UWM IRB documents or notifications sent to Diana Lenhardt for the CSM study file. |
| **Study Closure** | Danqing Hu to initiate study closure. Danqing to notify Diana Lenhardt of study closure. |

# Appendix E: TreatQuest® User Survey

First, we want to thank you for participating in this survey about the TreatQuest website.Your responses will be kept strictly confidential and be used for research purpose only. Only aggregated group level will be reported.

This survey will ask questions on how you like the TreatQuest website. To answer a question, please click the option following each question which best describes your situation. We are looking for your honest opinion on how this website may be able to help patients like you. The survey takes about 10 to 20 minutes. Your participation in this study is comorbiditypletely voluntary. If you have questions about the survey, please contact Dr. Hemant Jain at 414-229-4832 or by email at jain@uwm.edu. Your feedback will help developer of TreatQuest improve this website to better serve more users like you in the future.

Part I Questions about your background

1. What is the highest level of your education?
   - a) Doctoral Degree
   - b) Master Degree.
   - c) 4-Year College
   - d) 2-Year College
   - e) High School
   - f) Less than High School
   - g) Other

2. How often do you use the internet?
   - Very Often like on daily basis
   - Often like few times a week
   - Occasionally like once or twice a month
   - Seldom like once or twice a year
   - Never like not use it at any place

3. Do you use the internet to search for health/medical related information?
   - Yes
   - No
   - Not Applicable

4. How comfortable do you feel using information from the internet to communicate with a physician?

- Very comfortable
- Comfortable
- Not comfortable
- Not use internet information at all

5. Do you agree that information from the internet can help you make health/treatment related decisions?

- Strongly agree
- Agree
- Uncertain
- Disagree
- Strongly disagree

6. Do you think information provided by a physician is sufficient?

- Strongly agree as they are experts.
- Agree
- Uncertain
- Disagree. I sometimes look for a second option. .
- Strongly disagree. I always look for a second option

Part II   Questions about **My TreatQuest**

The following statements describe specific features of **My TreatQuest** page that you have reviewed. Please indicate how they describe your experience by selecting from the five agreement levels.

|  | Strongly agree | Agree | Uncertain | Disagree | Strongly disagree |
|---|---|---|---|---|---|
| 7. Education material in **My TreatQuest** page is very informative. |  |  |  |  |  |
| 8. Education material in **My TreatQuest** page can help me communicate with a physician? |  |  |  |  |  |

Part III  Questions about **Treatment Wizards**

The following statements describe specific features of **Treatment Wizards** page that you have reviewed. Please indicate how they describe your experience by selecting from the five agreement levels.

|  | Strongly agree | Agree | Uncertain | Disagree | Strongly disagree |
|---|---|---|---|---|---|
| 9. The **Treatment Wizards** provided a helpful guide to my treatment options. |  |  |  |  |  |
| 10. Each step in the **Treatment Wizards** gave me sufficiently clear explanation. |  |  |  |  |  |
| 11. By using the **Treatment Wizards**, I was able to find the exact information that I was looking for. |  |  |  |  |  |
| 12. The **Treatment Wizards** was helpful in discussing my treatment options with a physician. |  |  |  |  |  |

Part IV  Questions about **Information for Patient**

The following statements describe specific features of **Information for Patient**
page that you have reviewed. Please indicate how they describe your experience
by selecting from the five agreement levels.

| | Strongly agree | Agree | Uncertain | Disagree | Strongly disagree |
|---|---|---|---|---|---|
| 13. On the Information for Patient page, the *Similar Cases and Treatments Used* section helped me make treatment–related decisions. | | | | | |
| 14. On the Information for Patient page, the *Similar Cases and Treatments Used* section helped me communicate about treatment options with a physician. | | | | | |
| 15. On the Information for Patient page, the *Similar Cases and Treatments Used* section is informative. | | | | | |
| 16. On the Information for Patient page, the *Your Treatment Options and Evidences* section is informative. | | | | | |
| 17. On the Information for Patient page, the *Your Treatment Options and Evidences* section helped me communicate with a physician in regards to treatment options. | | | | | |
| 18. On the Information for Patient page, the *Your Treatment Options and Evidences* section helped me make treatment decisions. | | | | | |
| 19. The Nomogram tool is an informative tool to use. | | | | | |
| 20. The Nomogram tool helped me communicate with a physician. | | | | | |
| 21. The Nomogram tool helped me make treatment decisions. | | | | | |
| 22.On the Information for Patient page, the *Statistics* section is very informative. | | | | | |
| 23. On the Information for Patient page, the *Frequently Asked Questions and Answers* is useful. | | | | | |
| 24. On the Information for Patient page, the *Questions to Ask My Doctor* section helped me communicate with a physician. | | | | | |

Part V   Questions about **Search** and other functions

25. The Search function at the top of each page is easy to use.

- ● Strongly agree
- ● Agree
- ● Uncertain
- ● Disagree
- ● Strongly disagree

26. The list of websites in the **Search** functionincluded all the major websites related to lung cancer.

- ● Strongly agree
- ● Agree
- ● Uncertain
- ● Disagree
- ● Strongly disagree

27. What are the other websites you use to look for lung cancer-related treatment information?

28. On the **Knowledge Resources** page, the similar case search criteria are easy to understand.

- ● Strongly agree
- ● Agree
- ● Uncertain
- ● Disagree
- ● Strongly disagree

29. On the **Knowledge Resource** page, which section was the most helpful for your treatment decision?

- Similar Cases and Treatments Used Based On SEER Data
- Treatment Option from NCI
- Statistics
- Guidelines
- Nomogram

Part VI Questions about TreatQuest website in general

| | Strongly agree | Agree | Uncertain | Disagree | Strongly disagree |
|---|---|---|---|---|---|
| 30. TreatQuest website is easy to use. | | | | | |
| 31. Navigating the TreatQuest website is easy. | | | | | |
| 32. The content of the TreatQuest website is well organized. | | | | | |
| 33. The TreatQuest website has a consistent look and feel. | | | | | |
| 34. TreatQuest website contains most treatment related information that I'm interested in. | | | | | |
| 35. The evidence-based information that TreatQuest provided helped me to make decisions regarding my treatment options. | | | | | |

36. How likely are you to recommend TreatQuest to a patient or family member of a patient in the future?

- Very likely
- Somewhat likely
- Unlikely
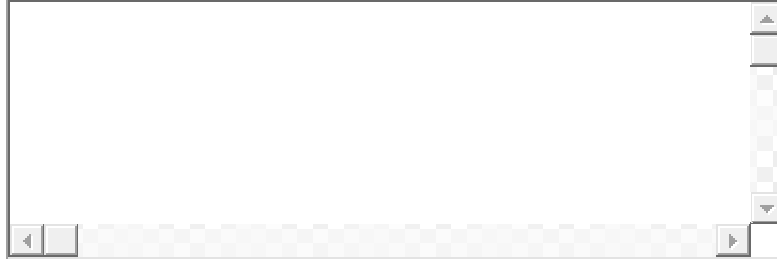
37. How likely are you to use TreatQuest as your primary source for getting treatment related information?

- Very likely
- Somewhat likely
- Unlikely
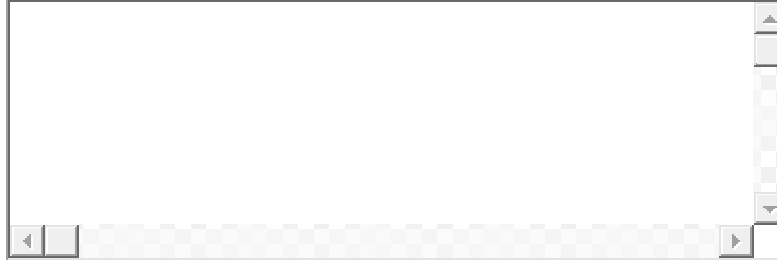
38. Do you want other non-treatment related information, such as diagnosis and risk factor, to be included in the TreatQuest website?

- ● Yes
- ● No

39. Regarding your treatment decision, what kind of information affected you the most?

40. What changes or additional features would you suggest for this website?

End of the survey. Thanks for your feedback.

# Appendix F: TreatQuest®:  User Survey Results

## Part I Questions about Your Background

**1. What is the highest level of your education?**

| | | |
|---|---|---|
| Doctoral Degree | **0** | 0% |
| Master Degree | **1** | 20% |
| 4-Year College | **2** | 40% |
| 2-Year College | **1** | 20% |
| High School | **1** | 20% |
| Less than High School | **0** | 0% |
| Other | **0** | 0% |

**2. How often do you use the internet ?**

| | | |
|---|---|---|
| Very Often, like on daily basis | **2** | 40% |
| Often, like few times a week | **2** | 40% |
| Occasionally, like once or twice a month | **0** | 0% |
| Seldom, like once or twice a year | **0** | 0% |
| Never like not use it at all | **1** | 20% |

**3. Do you use the internet to search for health/medical related information ?**

| | | |
|---|---|---|
| Yes | **3** | 60% |
| No | **2** | 40% |

**4. How comfortable do you feel using information from the internet to communicate with a physician?**

| | | |
|---|---|---|
| Very comfortable | **1** | 20% |
| Comfortable | **4** | 80% |
| Not comfortable | **0** | 0% |
| Not use internet information at all | **0** | 0% |

**5. Do you agree that information from the internet can help you make health/treatment related decisions?**

| | | |
|---|---|---|
| Strongly agree | **1** | 20% |
| Agree | **4** | 80% |
| Uncertain | **0** | 0% |
| Disagree | **0** | 0% |
| Strongly disagree | **0** | 0% |

**6. Do you think information provided by your physician is sufficient?**

| | | |
|---|---|---|
| Strongly agree as they are experts | **0** | 0% |
| Agree | **2** | 40% |
| Uncertain | **1** | 20% |

Disagree. I sometimes look for a second option. **2** 40%

Strongly disagree. I always look for a second option. **0**

## Part II Questions about My TreatQuest

The following statements describe specific features of My TreatQuest page that you have reviewed. Please indicate how they describe your experience by selecting from the five agreement levels.

**7. Education material in My TreatQuest page is very informative.**

| | | |
|---|---|---|
| Strongly Agree | **2** | 40% |
| Agree | **3** | 60% |
| Uncertain | **0** | 0% |
| Disagree | **0** | 0% |
| Strongly Disagree | **0** | 0% |

**8. Education material in My TreatQuest page can help me communicate with a physician.**

| | | |
|---|---|---|
| Strongly Agree | **2** | 40% |
| Agree | **3** | 60% |
| Uncertain | **0** | 0% |
| Disagree | **0** | 0% |
| Strongly Disagree | **0** | 0% |

# Part III Questions about Treatment Wizards

The following statements describe specific features of Treatment Wizards page that you have reviewed. Please indicate how they describe your experience by selecting from the five agreement levels.

**9. The Treatment Wizards provided a helpful guide of my treatment options.**

| | | |
|---|---|---|
| Strongly Agree | **3** | 60% |
| Agree | **2** | 40% |
| Uncertain | **0** | 0% |
| Disagree | **0** | 0% |
| Strongly Disagree | **0** | 0% |

**10. Each step in the Treatment Wizards gave me sufficiently clear explanation.**

| | | |
|---|---|---|
| Strongly Agree | **2** | 40% |
| Agree | **3** | 60% |
| Uncertain | **0** | 0% |
| Disagree | **0** | 0% |
| Strongly Disagree | **0** | 0% |

**11.By using the Treatment Wizards, I was able to find the exact information that I was looking for.**

| | | |
|---|---|---|
| Strongly Agree | **0** | 0% |
| Agree | **5** | 100% |
| Uncertain | **0** | 0% |
| Disagree | **0** | 0% |
| Strongly Disagree | **0** | 0% |

**12.The Treatment Wizards was helpful in discussing my treatment options with a physician.**

| | | |
|---|---|---|
| Strongly Agree | **0** | 0% |
| Agree | **5** | 100% |
| Uncertain | **0** | 0% |

Disagree                                    **0**    0%

Strongly Disagree                           **0**    0%


# Part IV Questions about Information for Patient

The following statements describe specific features of Information for Patient page that you have reviewed. Please indicate how they describe your experience by selecting from the five agreement levels.

**13. On the Information for Patient page, the Similar Cases and Treatments Used section helped me make treatment–related decisions.**

Strongly Agree                              **1**    20%

Agree                                       **4**    80%

Uncertain                                   **0**    0%

Disagree                                    **0**    0%

Strongly Disagree                           **0**    0%

**14. On the Information for Patient page, the Similar Cases and Treatments Used section helped me communicate about treatment options with a physician.**

Strongly Agree                              **1**    20%

Agree                                       **4**    80%

Uncertain                                   **0**    0%

Disagree                                    **0**    0%

Strongly Disagree                           **0**    0%

**15. On the Information for Patient page, the Similar Cases and Treatments Used section is informative.**

Strongly Agree                              **2**    40%

Agree                                       **3**    60%

Uncertain                                   **0**    0%

Disagree                                    **0**    0%

Strongly Disagree                           **0**    0%

**16. On the Information for Patient page, the Your Treatment Options and Evidences section is informative.**

Strongly Agree                              **1**    20%

Agree                                       **4**    80%

Uncertain                                   **0**    0%

Disagree                                    **0**    0%

Strongly Disagree                           **0**    0%

**17. On the Information for Patient page, the Your Treatment Options and Evidences section helped me communicate with a physician in regards to treatment options.**

Strongly Agree                              **1**    20%

Agree                                       **4**    80%

Uncertain                                   **0**    0%

Disagree                                    **0**    0%

Strongly Disagree                           **0**    0%

**18. On the Information for Patient page, the Your Treatment Options and Evidences section helped me make treatment decisions.**

Strongly Agree                              **1**    20%

| Agree | **4** | 80% |
|---|---|---|
| Uncertain | **0** | 0% |
| Disagree | **0** | 0% |
| Strongly Disagree | **0** | 0% |

**19. The Nomogram tool is an informative tool to use.**

| Strongly Agree | **0** | 0% |
|---|---|---|
| Agree | **4** | 80% |
| Uncertain | **1** | 20% |
| Disagree | **0** | 0% |
| Strongly Disagree | **0** | 0% |

**20. The Nomogram tool helped me communicate with a physician.**

| Strongly Agree | **0** | 0% |
|---|---|---|
| Agree | **4** | 80% |
| Uncertain | **1** | 20% |
| Disagree | **0** | 0% |
| Strongly Disagree | **0** | 0% |

**21. The Nomogram tool helped me make treatment decisions.**

| Strongly Agree | **0** | 0% |
|---|---|---|
| Agree | **4** | 80% |
| Uncertain | **1** | 20% |
| Disagree | **0** | 0% |
| Strongly Disagree | **0** | 0% |

**22. On the Information for Patient page, the Statistics section is very informative.**

| Strongly Agree | **0** | 0% |
|---|---|---|
| Agree | **3** | 60% |
| Uncertain | **1** | 20% |
| Disagree | **1** | 20% |
| Strongly Disagree | **0** | 0% |

**23. On the Information for Patient page, the Frequently Asked Questions and Answers is useful.**

| Strongly Agree | **0** | 0% |
|---|---|---|
| Agree | **5** | 100% |
| Uncertain | **0** | 0% |
| Disagree | **0** | 0% |
| Strongly Disagree | **0** | 0% |

**24. On the Information for Patient page, the Questions to Ask My Doctor section helped me communicate with a physician.**

| Strongly Agree | **0** | 0% |
|---|---|---|
| Agree | **5** | 100% |
| Uncertain | **0** | 0% |
| Disagree | **0** | 0% |
| Strongly Disagree | **0** | 0% |

## Part V Questions about Search and Other Functions

**25. The Search function at the top of each page is easy to use.**

| | | |
|---|---|---|
| Strongly agree | **3** | 60% |
| Agree | **2** | 40% |
| Uncertain | **0** | 0% |
| Disagree | **0** | 0% |
| Strongly disagree | **0** | 0% |

**26. The list of websites in the Search function included the major websites on which you did cancer related information research.**

| | | |
|---|---|---|
| Strongly agree | **1** | 20% |
| Agree | **4** | 80% |
| Uncertain | **0** | 0% |
| Disagree | **0** | 0% |
| Strongly disagree | **0** | 0% |

**27. What are the other websites you use to find lung cancer-related treatment information?**
Mayo Clinic

**28. On the Knowledge Resources page, the similar case search criteria are clear.**

| | | |
|---|---|---|
| Strongly agree | **0** | 0% |
| Agree | **5** | 100% |
| Uncertain | **0** | 0% |
| Disagree | **0** | 0% |
| Strongly disagree | **0** | 0% |

**29. On the Knowledge Resource page, which section was the most helpful for your treatment decision?**

| | | |
|---|---|---|
| Similar Cases and Treatments Used Based On SEER Data | **1** | 20% |
| Treatment Option from NCI | **2** | 40% |
| Statistics | **1** | 20% |
| Guidelines | **0** | 0% |
| Nomogram | **0** | 0% |

## Part VI Questions about TreatQuest Website in General

**30. TreatQuest website is easy to use.**

| | | |
|---|---|---|
| Strongly Agree | **1** | 20% |
| Agree | **4** | 80% |
| Uncertain | **0** | 0% |
| Disagree | **0** | 0% |
| Strongly Disagree | **0** | 0% |

**31. Navigating the TreatQuest website is easy.**

| | | |
|---|---|---|
| Strongly Agree | **1** | 20% |
| Agree | **4** | 80% |
| Uncertain | **0** | 0% |
| Disagree | **0** | 0% |
| Strongly Disagree | **0** | 0% |

**32. The content of the TreatQuest website is well organized.**

| | | |
|---|---|---|
| Strongly Agree | **1** | 20% |
| Agree | **4** | 80% |
| Uncertain | **0** | 0% |
| Disagree | **0** | 0% |
| Strongly Disagree | **0** | 0% |

**33. The TreatQuest website has a consistent look and feel.**

| | | |
|---|---|---|
| Strongly Agree | **1** | 20% |
| Agree | **4** | 80% |
| Uncertain | **0** | 0% |
| Disagree | **0** | 0% |
| Strongly Disagree | **0** | 0% |

**34. TreatQuest website contains most treatment related information that I'm interested in.**

| | | |
|---|---|---|
| Strongly Agree | **1** | 20% |
| Agree | **3** | 60% |
| Uncertain | **1** | 20% |
| Disagree | **0** | 0% |
| Strongly Disagree | **0** | 0% |

**35. The evidence-based information that TreatQuest provided helped me to make decisions regarding my treatment options.**

| | | |
|---|---|---|
| Strongly Agree | **1** | 20% |
| Agree | **3** | 60% |
| Uncertain | **1** | 20% |
| Disagree | **0** | 0% |
| Strongly Disagree | **0** | 0% |

**36. How likely are you to recommend TreatQuest to a patient or family member of a patient in the future?**

| | | |
|---|---|---|
| Very likely | **4** | 80% |
| Somewhat likely | **1** | 20% |
| Unlikely | **0** | 0% |

**37. How likely are you to use TreatQuest as your primary source for getting treatment related information?**

| | | |
|---|---|---|
| Very likely | **1** | 20% |
| Somewhat likely | **4** | 80% |
| Unlikely | **0** | 0% |

**38. Do you want other non-treatment related information, such as diagnosis and risk factor, to be included in the TreatQuest website?**

| | | |
|---|---|---|
| Yes | **3** | 60% |
| No | **2** | 40% |

**39. Regarding your treatment decision, what kind of information affected you the most ?**
side affect, prolong the overall survivalDOCTOR OPINIONphysician's opinion

**40. What changes or additional features would you suggest for this website?**
NONEnone

**Curriculum Vitae**

## Danqing Hu

Place of Birth: Luoyang, Henan Province, China
E-mail: dhu@uwm.edu

## EDUCATION

PhD Student in Medical Informatics, University of Wisconsin-Milwaukee, Milwaukee, WI. Dissertation Title: Patient-Oriented Evidence-Based Treatment Decision Support System (TreatQuest®) for Lung Cancer.

Master of Technology in Computer Technology, 2001, Kent State University, Kent, OH.

MS in Electronic Engineering, 1995, National University of Defense Technology, Changsha, China.

BS in Electronic Engineering, 1992, National University of Defense Technology, Changsha, China.

## PROFESSIONAL EXPERIENCE

2013.5 - present, Senior Program Developer, Henry Schein Inc., Milwaukee, WI.

2005.11- 2012.5, Programmer Analyst, DentaQuest, LLC, Mequon, WI.

2001.6 - 2004.8, Software Engineer, ChemImage Corporation, Pittsburgh, PA

2000.9 - 2001.6, Teaching Assistant, School of Technology, Kent State University, Kent, Ohio.

1995.8 - 1999.5, Lecturer, Department of Electrical & Mechanic Engineering, National University of Defense Technology, Changsha, China.

## PUBLICATIONS

Hu, Danqinq, Jain, Hemant. "TreatQuest®:Patient-Oriented evidence-based treatments decision support system". AMIA 2013 Poster Accepted.

Hu, Danqing, Junhong Zhou, and Runsheng Wang. "Hierarchical recognition methods for multi-class objects-dynamic binary tree and dynamic multi-branch tree." In Signal Processing, *1996., 3rd International Conference on,* vol. 2, pp. 1284-1287. IEEE, 1996

## AWARDS

UWM BHIRI Graduate Research Award (2013)

UWM Chancellor's Graduate Student Award (2005, 2006, 2007, 2008)

Guanghua Graduate Student Award (1993)