RAMIFICATIONS OF WEB-BASED HEALTH ASSESSMENT TOOLS ON CONSUMER BEHAVIORS AND HEALTH OUTCOMES

by

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February 2010

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ABSTRACT

With the explosion of Internet as a major transformational tool for the provision of health information and care, little is known about its effects on consumer health behaviors and health outcomes (Weaver, Thompson, Weaver, & Hopkins, 2009). Because health-related websites are expanding consumer access to medical information once only available to physicians (Herrick, 2005), there is a need to develop a recommended plan that incorporates the use of Internet-based self-assessment tools into quality health management. A panel of 26 experts in health care throughout the United States participated in a qualitative Delphi study to reach a consensus on potential health benefits and risks of web-based consumer health assessment tools as well as provide recommendations for safe and effective use of such tools. The goal of the study was to discover the flaws and strengths in the current system, and ultimately provide recommendations for the transformation and optimal use of Internet-based health information and tools by consumers and health care providers.

DEDICATION

I want to dedicate this dissertation to my family, close friends, mentor, and the physicians who invested countless hours in part of this study. A special dedication to my two greatest sources of inspiration and unremitting energy, my son Robert and mother Lilya, whose love, support, and unyielding belief in me never wavered; and to my confidant and best friend, Laurent, who spent endless hours teaching me Excel®, reviewing my work, and fixing my typos, and never doubting for a second that this study would come to its full and successful realization. Thank you! I am so grateful and love you all so much!

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CHAPTER 1: INTRODUCTION

Web-based health assessment tools can be defined as electronic interfaces that enable consumers to assess and diagnose medical conditions based on identified symptoms without the involvement of a health care professional (Demetrakakes, 2003). Potential health assessment sources include: websites with automated modules that prompt users to enter information about symptoms, yielding possible conditions as a result; informational sites that describe symptoms associated with medical conditions; and consumer blogs that promote discussion of symptoms and conditions without the electronic presence or oversight of medical personnel. Tools such as these are common on the Internet, making self-diagnosis easier than ever before (Demetrakakes, 2003).

Internet health assessments are widely available to consumers to use as a basis for deciding which symptoms require medical consultation (Tyson, 2000). Using the Internet, patients can obtain health information that enables them to self-diagnose and decide for themselves which symptoms or conditions need a consultation or office visit with a physician or can result in self-treatment (Herrick, 2005). Uninsured consumers who do not have cost-effective access to health care professionals rely on the Internet for self-diagnosis and treatment; such consumers often lack the knowledge to make informed decisions (Hardey, 1999; Lorence & Abraham, 2006).

Consumers are not trained to self-diagnose potential conditions properly (Hardey, 1999; Lorence & Abraham, 2006) or accurately identify physical signs (Xu, Schwartz, Monsur, Northrup, & Neale, 2004). As the use of the Internet for health information becomes more widespread, so does the risk to the general consumer quality of care

(Paidakula, 2006) because of incorrect or misleading information (Risk & Dzenowagis, 2001) as well as a growth in the number of health consumers who will either seek unnecessary and costly urgent care (Shrieves, 2009) or cease or decrease physician access altogether (Paidakula, 2006).

Background of the Problem

With the distribution of medical information to over 160 million people in the United States (Harris Poll, 2007; Rajendran, 2001), the Internet has been rapidly changing the consumer's view of medicine by providing a key opportunity for consumers and patients to become actively involved in the provision of his or her health care (Forkner-Dunn, 2003). Medical websites exist to help consumers use symptoms to self-diagnose illnesses and decide which symptoms require consultations with medical personnel (Herrick, 2005; Tyson, 2000). Internet sources have been influential as they have often been the basis of obtaining health information and making health decisions (Forkner-Dunn, 2003). In a survey that focused on Internet-based health information, 41% of respondents claimed that the Internet did affect their health care decisions, including whether to go to a doctor, treat an illness, or question their doctor (Forkner-Dunn, 2003).

As consumers become more reliant on the use of the Internet for medical self-diagnosis, the influence of web-based health assessment tools on the patient's behavior in seeking further advice from a doctor should be highlighted. Jones (2000) showed only one out of every 40 self-diagnoses resulted in a patient making an office visit for a medical consultation. With Internet self-diagnosis being so prominent in today's culture, a new term, cyberchondria, has been created to describe the phenomenon of patients who

use the Internet as a self-diagnostic tool to uncover potentially life threatening conditions causing them to unnecessarily spend valuable health care dollars on emergency room visits or specialist assistance (Shrieves, 2009). The practice, according to Shrieves, has become quite common. Physicians at Centra Care, a health care chain in Florida providing urgent care, say that at least one cyberchondriac per day is seen at their facility (Shrieves, 2009).

With more than 160 million Americans using the Internet to seek health information (Harris Poll, 2007) and more than 54 million results found in Google (2007) for the term health assessment tools, there is social concern about the yet-undetermined effects the Internet has had and will continue to have on patient behaviors and health outcomes. Whereas the growing availability and use of Internet health tools can benefit the global expansion of consumer awareness, the tools may also expand the chance of consumer health risks associated with a breakdown in the patient/physician relationship because of the growing number of consumers not seeking help or advice of a physician after self-diagnosis (Kerka, 2003).

Using the Internet, patients can obtain health information that enables them to self-diagnose and decide for themselves which symptoms or conditions need a consultation or office visit with a physician and which can be self-treated (Herrick, 2005). Uninsured consumers who do not have cost-effective access to health care professionals rely on the Internet for self-diagnosis and treatment, often lacking the knowledge to make informed decisions (Hardey, 1999; Lorence & Abraham, 2006). As the use of the Internet for health information becomes more widespread, risk to the overall consumer quality of care increases (Paidakula, 2006) resulting from incorrect or

misleading information (Risk & Dzenowagis, 2001) and a growing number of health consumers who will stop consulting physicians (Paidakula, 2006).

Problem Statement

The problem is that using the Internet as an information source for medical and health-related information may pose a risk (Lorence & Abraham, 2006) to consumers who may rely on the information to self-diagnose and self-medicate (Herrick, 2005). Consumers do not have the knowledge or training to make informed decisions about their health or successfully diagnose and treat themselves (Hardey, 1999; Lorence & Abraham, 2006). Subsequently, consumers may choose to self-medicate using over-the-counter or self-obtained medications, resulting in a disruption in the patient/physician relationship (Herrick, 2005).

The general problem is that medical leaders cannot ensure a safe and quality health care environment based on the increasing proportion of patient/physician disruptions (Herrick, 2005) as a growing number of consumers using the Internet continue to self-diagnose and decide which symptoms require consultations with medical personnel (Herrick, 2005; Tyson, 2000). Specifically, because health-related websites are expanding consumer access to medical information once only available to physicians (Herrick, 2005), there is a need to develop a recommended plan that incorporates the use of Internet-based self-assessment tools into quality health management. A panel of experts in health care throughout the United States was requested to participate in a qualitative Delphi study to reach a consensus on potential health benefits and risks of web-based consumer health assessment tools as well as provide recommendations for safe and effective use of such tools.

Purpose of the Study

The primary purpose of the current qualitative study was to explore expert opinions, values, perceptions, and feelings of health care providers about future ramifications of web-based health assessment tools including potential health benefits and risks that such tools can have on patient health behaviors and health outcomes (Qualitative Research Consultants Association, 2007). The current study was conducted to also explore recommendations for best practices in incorporating web-based health assessment tools into quality health care and continuing health management. To understand how to ensure the needs of health consumers are met, a panel of experts in health care participated in a qualitative Delphi study. Participants relied on their experiences, values, perceptions, and feelings to reach a consensus on the potential health benefits and risks of web-based consumer health assessment tools as well as provide recommendations for safe and effective use of such tools.

The Delphi method is used to form a panel of selected experts who represent a broad range of opinions on issues and the topic studied and allows the researcher to conduct surveys with the experts using a series of structured questionnaires and feedback reports (Loo, 2002). The Delphi method is a multi-phase approach that starts with a phase in which the subject matter is explored, allowing each panel expert to provide insights into questions about the subject matter. The second and third phases allow panelists to discuss (agree or disagree) the responses and reach consensus using terms of importance, feasibility, and similarity. The closing phase is the final evaluation and presentation of the panel's responses. The Delphi was suitable for the current study because the method allows a rapid and systematic collection of expert opinions and insights surrounding a

specific set of complex human circumstances (Linstone & Turoff, 2002; Loo, 2002). As an alternative method, a quantitative Delphi study would not be suitable because quantitative studies are used to seek evidence to support a hypothesis rather than attempt to understand complex human situations as a qualitative study does (Linstone & Turoff, 2002; Loo, 2002). Participants in the study consisted of 26 primary care and specialty physicians selected throughout the United States.

Study Significance

Medical leaders cannot ensure a safe and quality health care environment because of increasing patient/physician disruptions (Herrick, 2005) that include a growing number of consumers using the Internet to self-diagnose and decide which symptoms require consultations with medical personnel (Herrick, 2005; Tyson, 2000). Health-related websites are expanding consumer access to medical information that was once only available to physicians (Herrick, 2005). The significance of the current study is that it will offer a health-care provider view of identified consumer health benefits and risks that can be used as the groundwork in future studies. The study findings could also assist medical leaders as they seek to develop health care plans that incorporate the use of Internet-based health-assessment tools into quality health management shared between the doctor and patient.

Significance to Leadership

Leadership is the foundation of an organization, encompassing its leaders and followers (Fuchs, 2007). Leadership is also the foundation of health care, as the provision of health care occurs at an organizational level. The U.S. health care system is in need of change (Frank, 2007). In its current state, it is a non-system that leaves many gaps in

coverage. As medical insurance rates rise and more employers eliminate coverage because of unaffordable premiums, an increasing number of people become uninsured and unable to pay for or have access to health care (University of Maine, 2001). The current health care system in the United States is also the most expensive system in the world and currently costs the nation more than \$2 trillion per year (Frank, 2007). As access and cost continue to be compelling issues for the nation, leadership of the country needs to understand better how the Internet is being used for health care related issues and the potential health benefits, strengths, risks, dangers, and outcomes that such utilization can have on the nation.

The current study is significant because the findings may enable the development of a plan that incorporates recommendations for safe and effective uses of Internet-based health-assessment tools by adult consumers. The focus of leadership is on the ability to break new ground and find innovation, go beyond what is known, and help to define and build the future (Darling & Beebe, 2007). An important purpose of the current study was to help health care leaders break new ground, go beyond the known, and craft the future of online consumer health tools based on recommendations that were identified as a result of the findings from the study.

Significance to Future Research

With theoretical underpinnings of the appreciative inquiry model (Bush & Korrapati, 2004), the current study had enabled the discovery of strengths and flaws in the current system that could ultimately lead to the transformation and optimal use of Internet-based health information and tools. The predictions on how web-based health assessment tools could positively and negatively affect stakeholders could enable future

studies about the design of action plans and changes that need to be made to maximize the strengths of the Internet while minimizing the weaknesses. The contributions of the current study could support future global studies and leadership initiatives to improve how health information is managed, disseminated, and used globally through the transformational power of open communication, trust, and support of consumers, health care professionals, and world-wide leaders.

Nature of the Study

The current qualitative Delphi study was conducted to investigate current and future ramifications of web-based health assessment tools on consumers by exploring the opinions of health care professionals on the health benefits and risks that such tools have on patient health behaviors and health outcomes. The Delphi method is a technique that allows a group of experts to explore, discuss, and reach consensus on a complex problem (Linstone & Turoff, 2002). Delphi was suitable to the current study because it is a systematic approach for gathering data and formulating an informed opinion about the future ramifications of web-based health assessment tools and developing recommendations for best practices by surveying a panel of health care experts from around the nation.

The Delphi method brings together an anonymous panel of selected experts who represent diverse and broad spectrums of opinions on topics and issues being explored. The method allows the panel to be surveyed using a series of structured questionnaires and feedback loops (Loo, 2002). The Delphi method (Linstone & Turoff, 2002) consists of four unique phases. In the first phase, which is intended to explore the subject matter studied, each panel expert provides insights into the questions about the issue. The

second phase allows panelists to agree or disagree and reach an understanding of how the group sees the issue in terms of its importance, feasibility, and similarity (Linstone & Turoff, 2002). According to Linstone and Turoff, "if there is significant disagreement, then that disagreement is explored in the third phase to bring out the underlying reasons for the differences and possibly to evaluate them" (p. 3). The closing phase is the final evaluation of the panel's responses.

The Delphi method involves reiterative probing through which data are gathered by using a series of questionnaires delivered to a panel of geographically dispersed health care experts whose viewpoints will then be summarized statistically and presented back for additional insight. Through the first questionnaire the panel members were asked to respond to broad questions defining their personal beliefs and explaining their experience and understanding of the Internet. Panelists were also asked to describe possible problems, potential solutions and recommendations, and predictions for the future concerning the use of Internet health-assessment sites by consumers. Each subsequent questionnaire was built on responses to the preceding questionnaire. Questioning ended after three rounds, at which time consensus had been achieved among the participants.

The current Delphi study incorporated qualitative techniques that were used to explore expert opinions, values, perceptions, and feelings of health care providers about the potential health benefits and risks that web-based health assessment tools could have on consumers' health behaviors and health outcomes (Qualitative Research Consultants Association, 2007). Questions from round 1 were qualitative in nature, and were used for exploration. Response data from round 1 were analyzed and categorized by frequency or similarity of the response. Round 2 data were used to analyze the perceptions of

participants based on how they rated each category (from most important to least important) from round 1 using a Likert-type scale. In the analysis, rank was calculated for each category, and added thoughts or comments were captured. In round 3, the participants were presented with the final team ranking and asked to use their personal experiences and judgments to either agree or disagree with statements after considering the responses of their colleagues. Consensus or trends toward consensus were documented upon completion of this round as final analysis.

Appropriateness of Study

Research results and statistical data currently available on the effects of web-based health information and diagnostic tools on consumer health behaviors and subsequent outcomes have not been found. Although the use of a quantitative study could be an alternative to the current qualitative Delphi method, it was not appropriate for the current topic. The quantitative framework requires that behaviors and experiences of individuals be evaluated through statistical significance (Quaglia, 2006) rather than through the use of opinions, values, perceptions, and feelings (Qualitative Research Consultants Association, 2007). The topic of interest in the current study was the panelists' expert opinions that were gathered through open-ended inquiry that narrowed as increasing levels of consensus were reached. The Delphi method brings together thoughts and experiences of a group of health care experts. The experts' combined comments and responses to probing questions provided initial insights into how webbased tools could be used to enhance consumer health behaviors and outcomes while minimizing risks.

Medical leaders involved in health care cannot ensure quality health care because of the consumer's growing use of the Internet for self-education, diagnosis, and medication, which results in them not seeking help or advice of a physician (Kerka, 2003). By surveying and gathering input from health care providers, near consensus was achieved regarding specific risks and benefits that web-based health assessment tools may have on consumer behaviors. The current study also resulted in recommendations for best practices in incorporating web-based health assessment tools into quality health care and continuing health management as well as future related studies.

Research Questions

Health-related websites are expanding consumer access to medical information and helping consumers use symptoms to self-diagnose illnesses and decide which symptoms require consultations with medical personnel (Herrick, 2005; Tyson, 2000). Study results have proven that the Internet affects consumer health care decisions, including whether to go to a doctor, self-treat an illness, or question a doctor (Forkner-Dunn, 2003). A growing number of consumers using the Internet continue to self-diagnose and decide which symptoms require consultations with medical personnel, which interferes with medical professionals; ability to ensure a safe and quality health care environment (Herrick, 2005; Tyson, 2000). As consumers become more reliant on the use of the Internet for health care self-services, the impact of web-based health assessment tools on the patient's behavior and health outcomes should be better understood from the viewpoint of a health care professional. Specifically, there is a need to develop a recommended plan that incorporates the use of Internet-based health-assessment tools into quality health management.

To understand how to ensure the needs of health consumers are met, the following questions served as guidelines for the current study as well as the basis of inquiries submitted to the study panel experts:

- 1. How has the Internet changed health care?
- 2. Can self-help and health information websites influence consumer health behaviors and health outcomes?
- 3. In your experience, what have been some health risks associated with the use of self-help and health information websites by patients, consumers and caregivers?
- 4. In your experience, what have been the benefits of such tools?
- 5. Should the use of the Internet tools and websites be incorporated into health care practices?
- 6. How could health professionals including doctors, nurses, pharmacists and even health librarians be integrated into the web-based health information model to support consumers in need?

Theoretical Framework

The current research is in the area of health care delivery. Few studies, peerreviewed papers, or reports have been located on the use of the Internet for health
assessment and diagnosis by consumers and the direct effect it has on patient health
behaviors. No studies were found that examining the effects of web-based health
assessment tools on consumer health outcomes. No studies were found capturing the
health care provider views of potential health outcomes and risks of web-based consumer
health assessment tools or recommendations for safe and effective use of such tools.

Previous peer-reviewed reports and studies had been focused on studying consumer and doctor opinions related to patient education or direct-to-consumer marketing effect on patient/physician relationships. More recent studies have been focused on identifying consumer populations utilizing Internet-based health care information and how they use such information and tools. Findings from one study indicated that a considerable segment of consumers using the Internet for health information were engaging in treatment strategies that were not consistent with the recommendations of health care providers (Weaver, Thompson, Weaver, & Hopkins, 2009). The study findings were that 11.2% of the Internet health-information seekers either discontinued or refused treatment recommended by their physician.

Research has shown that those who actively seek information may have poorer coping skills (O'Grady, Witterman, & Wathen, 2008). Weaver, Thompson, Weaver, and Hopkins (2009) found that the Internet users who were non-adherent to medical advice and treatment recommendations also spent more time on the Internet seeking health information, ascribed greater importance to health information available from mass media, demonstrated greater reliance on social media and social community support, experienced a poorer quality of life, and reported possessing higher self-efficacy. Health outcomes, positive or negative, were not studied or documented in the Weaver, Thompson, Weaver, and Hopkins (2009) study.

In 2009, Buckley (2009) reported that young invincibles represented the largest group of uninsured people in the nation. As a result of the lack of health insurance, these 20-something-year-olds had chosen to use Internet resources such as WebMD to play the role of a physician (Buckley, 2009). As in the Weaver, Thompson, Weaver, and Hopkins

(2009) study, no reported health outcomes, positive or negative, had been studied or documented as part of Buckley's (2009) work. Colliver (2008) reported similar findings, stating that regardless of the risks imposed by the Internet as a self-treatment tool, Americans seem to be willing to make calculated health risks in the absence of health care and prescription drug coverage (Colliver, 2008). Like Buckley (2009), Colliver (2008) did not assess or report health outcomes as part of the work.

Studies have been conducted to show that rapid access to relevant health related information is highly beneficial as patients face challenges in making appointments to see their physicians and have limited time to discuss health care questions and concerns once they visit the office and finally see their physician (Tu & Cohen, 2008). Tu and Cohen showed that consumers researching their health concerns believed that the information on the Internet helped them to understand how they can treat their medical condition. In their analysis, Tu and Cohen (2008) discovered that four out of five health information seekers found information that helped them diagnose and treat a particular disease or condition.

Studies have shown that consumers are unable to accurately understand their physical signs and symptoms and report on them (Xu et al., 2004), and that only one out of 40 self-diagnoses results in a medical consult with a physician (Herrick, 2005). Studies have also shown that a growing number of consumers are using Internet tools to self-diagnose and treat while not seeking help or advice of a doctor after the self-diagnosis (Kerka, 2003). Tu and Cohen (2008) discovered that the trend to self-diagnose was particularly evident in responses from the Hispanic and African American communities. A possible explanation suggested was that these minority consumers may not have a doctor or health care provider that he or she see on a regular basis (Tu & Cohen, 2008).

Similarly, individuals without a regular health care provider found that gathering health information from other sources had a strong impact on their health behavior as well as their knowledge (Tu & Cohen, 2008). Studies have also been conducted to demonstrate that wide-spread use of the Internet for health information presents greater risk to the overall consumer quality of care as a growing numbers of health consumers will cease or decrease physician access (Paidakula, 2006).

Scope, Limitations, and Delimitations

The current study was conducted to explore the effects of web-based health-assessment tools on consumer health behaviors. The findings include insights and recommendations for safe and effective use of such tools. The scope of the study, along with the study limitations and delimitations, has been identified and is discussed herein. *Scope*

The scope of the current study was to focus on the effects that web-based health-assessment tools may have on consumer health decisions and outcomes as well as generate recommendations for safe and effective use of such tools by exploring the perceptions, experiences, and recommendations of health care professionals. One-hundred health care experts (physicians) were targeted for selection using the public social networking site LinkedIn. Physicians were limited to the United States and were selected by geographic locations and level of experience. Each was sent an invitation email (based on email availability) or LinkedIn notification soliciting participation in the Delphi study (see Appendix A). Of the 100 selected, 41 responding physicians matching the necessary study criteria were selected to participate and were requested to complete the Informed Consent Statement (see Appendix B).

The first in a series of questionnaires (see Appendix C) was emailed to the panel members with a target completion date and instructions on how and where to send the completed anonymous questionnaire. Of the 41 physicians who were initially emailed the first questionnaire, 26 panelists completed and returned the final first round survey within the specified time period. Two additional surveys were conducted in the Delphi study, for a total of three questionnaires sent to and received from the participating physicians. No financial incentives were offered for responding to questionnaires. Instead, a final report of study results was provided to all participants. The survey contained questions about use, effects of use (benefits and risks), overall experiences, and future recommendations regarding use of web-based health assessment tools.

Limitations

Participants' experience with the Internet may have influenced the results of the current study, as participants' comfort level with the web may have limited the results of the study. Participants may not have answered questions honestly. Their experience with patients who use of the Internet as a self-diagnostic tool may have also impact the study findings, as may the patients' reported usage, age, gender, and professional experience. Inadequate ability to measure responses or to correlate responses to risks and benefits may have also been limitations of the current study.

Delimitations

The delimitations of the current study included the participants' personal bias in the area of study as well as measurement limitations such as the participants' interpretation of intensity of responses. The majority of panelists was male, and may have represented a male point of view without the balance of an equal number of women.

While age may have influenced participant responses, it was not tracked for the purposes of the study. Similarly, geographic locality may have affected panel responses, yet it was also not tracked for the purposes of the current study.

Summary

With the growing use of the Internet and health-related websites expanding consumer access to medical information once only available to physicians (Herrick, 2005), a need exists to develop a plan that incorporates adult consumers' use of Internet-based self-assessment tools into quality health management. As consumers become more reliant on the use of Internet for self-diagnosis of medical conditions, the influence of diagnostic tools on the patient's behavior in seeking further advice from a doctor should be explored (Forkner-Dunn, 2003). The purpose of the current research was to apply the Delphi method to explore expert opinion about current and future ramifications of webbased health assessment tools including potential health benefits and risks that such tools can have on patient health behaviors and health outcomes. Additionally, the current study was conducted to explore recommendations for best practices in incorporating web-based health assessment tools into quality health care and continuing health management. Chapter 2 will present the literature review of the current study.

CHAPTER 2: LITERATURE REVIEW

The purpose of the current qualitative research study using the Delphi design was to discover an expert view of the future ramifications of web-based health assessment tools, including potential health benefits and risks that such tools can have on patient health behaviors and health outcomes. Additionally, the current study was conducted to explore recommendations for best practices in incorporating web-based health assessment tools into quality health care and continuing health management. The review of literature will provide insight into the historical overview leading up to the opportunities and challenges related to consumers and their use of web-based health-assessment tools.

The historical review that was conducted examined the consumer's orientation towards self-diagnosis and treatment, the availability of diagnostic and treatment tools via the worldwide web, and the changing landscape of the cost and access of health care. The overview provided a perspective on the growing availability of health information to consumers as well as regulations and guidelines of disseminating such information on the Internet. The overview established a rationale for analyzing potential opportunities and the hazards associated with web-based health assessment tools, thus assuring a safe and quality health care environment that incorporates the use of such tools by adult consumers and health care providers into quality health management.

Title Searches, Articles, Research Documents, and Journals

Initial searches of available information relative to consumer behavior and outcomes associated with the use web-based health assessment tools were conducted using the University of Phoenix Library SwetsWise Searcher search engine, which crawls

through search engines such as Google Scholar, EBSCOhost, ProQuest, and SAGE full-text collections. The review and literature indicated that the use of the Internet for health information and assessment is growing and that self-diagnosis and self-treatment are common. While web-based health tools provide opportunities and risk, the review and literature also indicated that not enough attention has been paid to the use of such tools and their impact on consumer health behaviors and subsequent outcomes.

Historical Overview

The historical overview will provide insight into the rise of technology in health care, challenges with consumer access to health care, and the growing consumer orientation towards self-diagnosis and treatment in the Unites States.

The Rise of Technology

The use of information systems in health care started in the mid 1950s, when financial and accounting business functions became automated (Thede, 2007). The early use of automation was workflow oriented and relied on the use of very big and expensive computer systems (Thede, 2007). According to Thede, the 1960s proved to be momentous years for the utilization and growth of automation in health care. In the early 1960s, the use of technology and automation in health care were expanding slowly, being implemented for patient care applications. By the mid 1960s, the value of automation was recognized by a limited number of health care organizations.

Health care providers' recognition of automation value can possibly be attributed to the fact that the U.S. Congress included Medicare and Medicaid as part of the Social Security Act and required nurses to document and provide care data in order to qualify for reimbursement (Thede, 2007). A select few hospitals started to develop their hospital

information systems during the 1960s; the rest of the industry remained slow to recognize the potential of automated information access as the market was not yet fully understood by manufacturers of computers. By the late 1960s, the market started to grow with hospital information systems including workflows and automation for patient diagnoses, care plans, patient information, and physician and nurse orders. The decade concluded with an attempt to develop the first integrated patient care technology solution – using POMR (problem-oriented medical records) focused on patient-centric care (Thede, 2007).

The 1970s showed growth of health care automation, with health departments and community organizations working on developing systems to produce reports required of them by government agencies (Thede, 2007). The POMR-based solution named PROMIS* (which stood for PRoblem Oriented Medical Information System) was first implemented at the time and provided insight into relationships between conditions and cost of care. PROMIS* did not gain wide use and acceptance until the 1990s, with the emergence of managed care.

Advances in computer systems occurred during the 1970s, and Intel developed a single chip (Polsson, 2008). The single chip was the beginning of personal computers. In the mid-70s, the Department of Health, Education, and Welfare held a conference on information systems for health care providers, with workshops to help agencies implement the technology internally for use in administration, reporting of statistics, and the analysis of cost (Thede, 2007). As the 1970s progressed, more and more health care organizations in various states started to develop and implement health care systems.

The 1980s and 1990s introduced the mass availability of personal computers, fax machines, printers, and copiers (Marples, 2004; Polsson, 2008). IBM built a smaller, standalone computer with more memory and a new DOS operating system developed by Microsoft. The 1990s also introduced the first personal digital assistant (PDA), the Intel processor, and Microsoft Windows (Polsson, 2008). Better interfaces for health care systems were also developed as the vision for broader market opportunity opened up (Thede, 2007). According to Thede, an economic recession slowed growth of projected sales. Lower costs became the driver to growth in sales. A shift from process-oriented to patient- and outcome-centric systems was seen, because of the change towards managed care and a focus on outcomes (Thede, 2007).

Capturing information at the point of care became increasingly possible and important as managed care was driving technology utilization (Thede, 2007). By the mid-90s, PDAs were starting to be utilized in hospitals to capture such information while the Health Insurance Portability and Accountability Act (HIPAA) was being passed by Congress. By the late 90s, the Internet had become a household name along with the next generation of affordable, faster, and more advanced personal computers (PCs) that allowed these households to gain access to anything from anywhere (Thede, 2007). All worldwide information boundaries were broken, leading to yet another technology milestone (Thede, 2007).

With the rise of the Internet and the next generation of affordable, fast, and interactive personal computers (PCs), came the health care technology explosion (Thede, 2007). Health care providers had easy access to laboratory and medical office systems, network and network management systems, web-based tele-medicine technology, email

and instant messenger for immediate interactions, web-based disaster recovery, backup, and storage for hassle-free and worry-free protection. Health care providers and consumers enjoyed the growing use and popularity of electronic data interchange (EDI), networked and stand-alone electronic medical records (EMR) and emergency medical services (EMS) systems, and more (Thede, 2007).

More advanced and secure technology, with wireless and mobile capabilities, enabled health care providers and patients to access anything, anytime, and anywhere (Thede, 2007). Technology such as the Internet had enabled doctors to simplify the practice of medicine, talk to patients, gain drug information at the tips of their fingers, and even submit an electronic prescription to a local pharmacy on behalf of a patient (Thede, 2007). The Internet has also provided fast access to health-related information to consumers and patients alike (Forkner-Dunn, 2003).

As a result of efficiency and effectiveness in processing data and running mathematical and statistical computations, computers have become the leading source of automated decision-making over time and across various fields (Uzoka & Famuyiwa, 2004). In medicine, complex health care dynamics exist that cannot be easily addressed by simple data processing and are very much still dependant on the experience and skills of professionals. The skills include the ability to make complex decisions such as identification of health care factors, the weighting of evidence, and the ability to evaluate alternatives and predict outcomes (Uzoka & Famuyiwa, 2004).

The Internet has been rapidly changing the consumer's perception of medicine by enabling the rapid distribution of massive information to nearly 100 million people in the United States (Rajendran, 2001). Google has 54,700,000 search results for health

assessment tools (2007) that include medical/hospital sites, privately owned and managed consumer sites, pharmaceutical web sites, consumer blogs, government sites, and on-line professional journals and publications.

Health Care Accessibility in the United States

The United States is the only Western country that does not offer access to nationally funded health care to all of its citizens (Padamsee, 2006). The country has been viewed to be positioned at the market-maximized side of Anderson's market-minimized/market-maximized continuum (Padamsee, 2006; Waruingi, 2006), as compared to other national health care systems. According to Fried and Gaydos (2002), Anderson put the United States at the market-maximized far-end of the continuum as a country that provided health care through a private market with minimal and limited government involvement. Anderson organized his market-minimized/market-maximized continuum based on the level of involvement that the government had in the financial and organizational elements of the health care system (Waruingi, 2008). According to Waruingi (2008, paragraph 1):

Anderson posited that an uneasy equilibrium exists between the public and private health care sectors; the degree to which a state centralizes financing and planning, and the relative size of its public sector determines its position on the continuum, as does the extent to which it intervenes in the operations of the economy itself.

Unlike market-minimized health care providing countries like the United Kingdom, in the United States, market-maximized health care is sold just like any other product or service. Consumers have control over the services they buy and what price they are willing to pay, and the allocation of resources is mainly driven by the current

market pricing (Padamsee, 2006). The market approach, according to Padamsee, has resulted in a system that is very complex from an administrative point of view and one that is provided through the piecing together of multiple systems that must somehow work together to cover the majority of the population.

The cost of health care in the Unites States continues to grow. It is projected to be close to \$5 trillion by the year 2020 (Sengupta, 2006). While there have been slow shifts arising out of state-level actions, traditionally the previous decades gave way to a market maximized system in which health care was provided and funded mostly by private payers, and in which the funding for health and health insurance most commonly came from individuals and employers (Waruingi, 2006).

According to Padamsee (2006), more than 60% of American citizens have health insurance that is partially or fully funded by an employer. Additionally, the Unites States also offers single-payer systems to specific populations of the market. Medicare insures roughly 20% of the U.S. population and is considered the largest single payer system in the United States. Medicare recipients are primarily of adults who are in the age group of 65 or older, those who are disabled, and those who have a permanent state of kidney failure (Padamsee, 2006) and is considered the largest single payer system in the United States.

Medicaid was created in 1965 alongside Medicare. Medicaid combines the finances at both the federal and state levels to provide insurance to people below a specific poverty level, including those who are children or fall in the age category of 65 and older, those who are disabled or blind, and those who receive financial assistance from the federal government (Padamsee, 2006). Other government programs at national,

state, and local levels provide supplemental coverage specific to children, military members, veterans, and federal employees (Padamsee, 2006).

Even with all the available health care coverage, there are still not enough jobs to ensure that everyone will have access to health care through such private sources. There are still more than 40 million Americans who are without insurance and for whom the ability to receive health care in very limited (Padamsee, 2006). Of those, more than 50% are working adults. These 40 million Americans can only access care if they pay for it directly out of their pockets, obtain it through the use of free public clinics, or seek charity care (Padamsee, 2006). In the past, health care was presumed to be guided by ethical and social responsibilities that dominated economic concerns such as the provision of care based on need and regardless of race, gender, sexual orientation, religion or ability to pay (Andersen, Rice, & Kominski, 1996)

In the U.S., the market-maximized system has been categorized as being unjust, discriminatory against those who are less advantaged and vulnerable, and wasting far more costs than any other nation (Waruingi, 2006). The quality of health care provided to patients has been viewed as having gaps, as the delivery of care is dependent on a patient's capability and desire to pay (Waruingi, 2006). With suboptimal quality and access, the current health care system in the United States is the most expensive system in the world.

In 2006, health care cost the nation roughly 14% of the gross national product, which is approximately \$2 trillion out of a total gross national product (GDP) of approximately \$12.5 trillion (Manchikanti, 2008). More than 30% (more than \$600 billion) of these funds were used for the administration of services and never seen by the

beneficiaries who need them most (Frank, 2007). Based on Frank's calculations, this is more than 21 other countries spend – each of which offers single-payer, tax-financed systems and have a life expectancy greater then what exists in the United States. The U.S. system also leaves many uninsured. In 2007, more than 40 million Americans did not have health insurance either because they were unemployed or had incomes that were too low to afford coverage and did not have assistance from employers or government to pay for coverage (Frank, 2007).

With the growing rate of the uninsured, health care in the U.S. is dramatically changing as a result of longer life spans and an increasing prevalence of chronic disease (Gutiérrez & Ranji, 2007). Between 2007 and 2008, the rate of uninsured people grew to roughly 86.7 million Americans under the age of 65 (Americans at Risk, 2009), leaving one in every three people uninsured. While the government is working on a centralized health care initiative to provide care to all citizens, the number of uninsured and underinsured in the United States continues to grow because of a tough economy and recent unemployment rates. Many are left without coverage as a result of either being laid off from work, personal choice, or a closure of a business or financial issues (Lebhertz, 2007). The U.S. health care system and all constituents will be even more impacted in respect to cost, access, and quality. As consumer demand increases, unemployment and uninsured rates rise, physician rates drop, medical costs continue to be measured based on outcomes and pharmacoeconomic studies. The need for medical services continues to grow because of a new cohort of aging patients and new generations of educated, sophisticated, Internet-capable consumers with exposure to direct-to-consumer advertising (Tufano, 2001).

According to Buckley (2009), the largest group of uninsured people in the nation is people in their 20s. Estimated to be more than 13.2 million in number in 2007, the young invincibles do not have insurance because of very high premiums and because they feel invincible because of their age (Buckley, 2009). As a result, many choose to use Internet resources such as WebMD to play the role of a physician (Buckley, 2009) and to self-diagnose and self-treat.

Consumers who are without health insurance coverage have a high tendency to use the Internet for health information (Bundorf, Wagner, Singer, & Baker, 2003) in efforts to self diagnose and self-medicate using potentially dangerous on-line pharmacies (Colliver, 2008). Many lack the knowledge to make informed decisions (Hardey, 1999; Lorence & Abraham, 2006). Regardless of the risks imposed by the Internet as a self-treatment tool, Americans without health care and prescription drug coverage seem to be willing to take a gamble and deal with the consequences (Colliver, 2008). As the use of the Internet for health information becomes more widespread, there is greater risk to the overall consumer quality of care (Paidakula, 2006) resulting from wrong or misleading information (Risk & Dzenowagis, 2001) and a growing numbers of health consumers who will not or cannot seek a physician's advice (Paidakula, 2006).

Consumer Orientation Towards Self-Diagnosis and Treatment

Consumers have a propensity towards self-diagnoses because of ease, privacy, and flexibility (Lewis, 2001) of finding diagnostic information within personal settings.

According to Lewis, consumers favor the option of self-testing and diagnosis because the options are viewed as more convenient and less expensive than visiting a doctor's office.

The self-diagnostic and monitoring devices market has been booming since the 1970s when the first at-home pregnancy kit was released (Lewis, 2001).

The consumer orientation towards self-diagnosis is not without flaws and may pose serious health implications for those who rely on the information rather than seek the advice of a health care professional (Lewis, 2001). The heavy utilization of home self-diagnostic devices has raised red flags with health care professionals (Lewis, 2001). With the recent shift to the Internet as a cost-effective and readily accessible tool for medical information and self-diagnosis, more patients are becoming actively involved in their own health care management (Levy & Strombeck, 2002).

Levy and Strombeck (2002) expected that consumers who are empowered by the Internet would be more actively involved in managing their health care by proactively engaging in self-diagnosis, testing, and self-medicating. Levy and Strombeck estimated that 80% of illnesses were handled through self-care. While there are negative implications and dangers of self treatment, the cost of health care could be significantly reduced if patients were able to successfully self-diagnose and self-treat using the Internet in the privacy of their own homes (Levy & Strombeck, 2002). The broad availability of eHealth tools such as web-based health education sources and diagnostic sites enables consumers to obtain simple and easy access to disease, drug, and health information they need when they need it (Levy & Strombeck, 2002).

Levy and Strombeck (2002) believed that the Internet had transformed standard health care practices and health education, enabling the quick facilitation and exchange of large amounts of information to diverse audiences and communities across the globe. The Internet had improved the ability to access information and obtain more efficacious

health care for the patient. Consumers could engage in their own care, access information and be better educated, and even become part of web-based communities that offer members support, advice, and the ability share their experiences (Levy & Strombeck, 2002). While Internet-based health assessment and management tools have been and continue to be developed, there are challenges with their success as it is difficult to predict and evaluate a consumer's capability to successfully use them and gauge the effectiveness and efficacy of their actions and subsequent health outcomes (Levy & Strombeck, 2002).

Health and the Internet

During the first decade of the 21st century, consumers were challenged with a fragile economy and were confronted with the financial burdens of increasing health care costs (Tu & Cohen, 2008). The increasing rates of health care services and insurance premiums have grown faster than people's incomes and have resulted in a growing rate of uninsured (Tu & Cohen, 2008). As more consumers face greater out-of-pocket expenses and greater financial burdens associated with obtaining access to care, it will become more likely that the Internet will play a key and possibly sole role in the provision of health care (Tu & Cohen, 2008).

There are benefits to using the Internet to seek health-related information. Over the last 25 years, the Internet has become the main source for health-related information made available directly to millions of users (Levy & Strombeck, 2002). Rapid access to limitless information empowers consumers to be more informed and allows patients to become more at ease with recommendations and treatment guidelines provided by physicians (Kalvaitis, 2009).

Health assessment tools from the Internet are available to consumers and patients to use as a basis for post-visit follow-up, self-education, and self-diagnosis, particularly in deciding which symptoms require consultations (Tyson, 2000). As a result, consumers can self-search, diagnose, and even treat without ever seeing or talking to a physician. Patients can use the Internet to access health care sites that enable them to self-diagnose and decide for themselves which symptoms or conditions need a consultation or office visit with a physician and which can be self-treated (Herrick, 2005).

A growing number of consumers are using such tools for self-diagnosis and treatment, while not seeking help or advice of a doctor after self-diagnosis (Kerka, 2003). Uninsured consumers who do not have cost-effective access to health care professionals rely on the Internet for self-diagnosis and treatment, yet often are lacking the knowledge to make informed decisions (Lorence & Abraham, 2006). Consumers access information independently or have it coming to them from employer-led programs, health campaigns, and even direct-to-consumer advertising (Tu & Cohen, 2008).

Rapid access to relevant health related information is highly beneficial. Patients face challenges in making appointments to see physicians and have limited time to discuss health care questions and concerns once they visit the office and finally see their physician (Tu & Cohen, 2008). As consumers become more reliant on the use of the Internet for self-diagnosis of medical conditions, the influence of web-based health assessment tools on the patient's behavior in seeking further advice from a doctor should be explored. Jones (2000) showed only one out of every 40 self-diagnoses resulted in a patient making an office visit for a medical consultation. As Internet self-diagnosis continues to grow in utilization, there is also concern that more patients who use the

Internet as a self-diagnostic tool may incorrectly identify potentially life-threatening conditions, causing them to spend valuable health care dollars unnecessarily on emergency room visits or specialists (Shrieves, 2009).

According to Levy and Stromback (2002), there will be an increasing growth of Internet users and the amount of health-related information on the web. With 54,700,000 results found in Google in 2007 and 18,000,000 for the term self-diagnosis in 2009, there is social concern about the yet-undetermined effects the Internet has and will continue to have on patient behaviors and health outcomes. While the growing availability and use of Internet health tools can benefit the global expansion of consumer awareness (Levy & Strombeck, 2002), the tools may also increase the chance of consumer health risks associated with a breakdown in the patient/physician relationship because of the growing number of consumers not seeking help or advice of a physician after self-diagnosis (Kerka, 2003).

Health Behaviors

As the Internet continues to emerge as a major transformational method for the provision of health information and care, questions remain about its effects on health behaviors and outcomes (Weaver et al., 2009). According to Wallston (1997), health behaviors constitute health-related actions impacting one's health status. Such activities include seeking information about care and physician visits as well as smoking and even drug use (Wallston, 1997). Such behaviors, either positive or negative, are reconciled by a perceived threat of a specific health outcome, by the barriers or benefits to taking a particular action, or by an expected reduction to threat as a result of taking action

(Cassell, Jackson, & Cheuvront, 1998) and represent the theoretical underpinnings or social learning theory.

Social learning theory states that the chance that a person will engage in particular behaviors is a result of that person's anticipation that such actions will generate specific outcomes as well as the perceived value of the resulting reinforcement (Wallston, 1997). This can be evidenced in the recent study by Weaver, Thompson, Weaver, and Hopkins (2009), which demonstrated that a considerate portion of consumers who were actively using the Internet to seek out health information were going against the recommendations of their health care providers and engaging in alternative treatment strategies such as discontinuation or refusal of treatment. The same study also showed that these same users demonstrated greater reliance on social media and web-based community support, experienced a poorer quality of life, and reported to have higher self-efficacy (Weaver et al., 2009).

Self-efficacy, a central part of social learning theory, represents a person's judgment of their own ability to perform activities resulting in specific outcomes. According to social learning theory, awareness is influenced by the informative function of modeling and are more likely to are more likely to adopt modeled behavior if it results in outcomes they value" (Bandura, 1977, p. 28). As such, self-efficacy can occur as a result of personal experience or from witnessing the successes of others and believing that they are capable of achieving the same outcomes and successes (Zullkosky, 2009). This subjective determination of one's abilities is also referred to as perception of control (Wallston, 1997). The more a person believes he or she is in control of a situation, the

more likely they are to engage in that behavior. According to Zullkosky (2009), having too high of an estimate in one's beliefs could cause physical injury.

Current Findings in Web-Based Health Information

Current findings in web-based health information include the explosion of web-based health information and tools, how these tools are utilized, the risks associated with such utilization, and regulatory activities currently in effect to minimize risks. This section discusses the current growth of the web for health-related activities, demonstrates how these tools are utilized by consumers and patients, exposes the possible risks associated with such utilization, and mentions current regulatory activities employed by the U.S. government to help minimize such risks.

Explosion of Web-Based Health

The Internet has been rapidly changing the consumer's view of medicine. Patients can obtain health information using the Internet that enables them to self-diagnose and decide for themselves which symptoms or conditions need a consultation or office visit with a physician and which can be self-treated (Herrick, 2005). Rapid distribution of medical information to millions of people in the United States (Rajendran, 2001) has been providing a significant opportunity for patients to become directly involved in their own health care (Forkner-Dunn, 2003).

Between the years 2001 to 2007, America saw a substantial growth in the number of adults seeking information about a specific health issue or concern (Tu & Cohen, 2008). More than 160 million people (more than 60% of American adults) independently obtained health information from various sources (Harris Poll, 2007). The Internet was the leading source for health information, primarily by those 65 and younger. Consumers

researching their health concerns said the available information helped them to understand better how an illness or specific condition could be treated (Tu & Cohen, 2008). Tu and Cohen discovered that four out of five health information seekers discovered information to help diagnose and treat a condition.

The trend to self-diagnose was particularly evident among the Hispanic and African American communities. Tu and Cohen (2008) suggested that these minority consumers might not have a dedicated health care provider who they see on a regular basis. Similarly, individuals without a regular health care provider found that gathering health information from other sources had a great effect on their health behaviors and knowledge (Tu & Cohen, 2008). The study results also revealed that individuals who sought personal health information were also active in searching for health information on behalf of other adults (including spouses and elderly parents) and children. Four out of five adults who sought health information on behalf of others also searched for similar information for themselves (Tu & Cohen, 2008).

Whether the information made available through the Internet provides greater value or risk to the consumers seeking to improve their health knowledge and behaviors is still unclear. Because of the lack of regulations and massive amounts of low-quality information, the use of the web can result in misunderstanding or misinterpretation of findings as well as self misdiagnosis and mistreatment (Potts & Wyatt, 2002). The explosion of access to health-related information via the web can also enhance a consumer's understanding of his or her condition, and can serve as a source of support through the use of social media technology such as patient health blogs (Potts & Wyatt, 2002).

Current Uses of Web-Based Health-Related Tools

Today's patients and consumers can obtain health-related information using the Internet. This information can enable them to self-diagnose and decide for themselves which symptoms or conditions need a consultation or office visit with a physician. It can also result in self-treatment (Herrick, 2005). Uninsured consumers who do not have cost-effective access to health care professionals rely on the Internet for self-diagnosis and treatment and often lack the knowledge to make informed decisions (Hardey, 1999; Lorence & Abraham, 2006). As the use of the Internet for health information becomes more widespread, there is greater risk to the overall consumer quality of care (Paidakula, 2006) resulting from wrong or misleading information (Risk & Dzenowagis, 2001) and a growing numbers of health consumers who will not seek advice from a physician (Paidakula, 2006).

The growing use of medical websites as real-time, interactive tools used for the provision of care services by consumers and patients offers consumers varying benefits that include convenience and access with limited boundaries (Martin, 2000). The health care revolution has also increased concerns that consumers may expose themselves to inaccurate information or endangerment (Potts & Wyatt, 2002). Certain providers may also use the technology for fraudulent purposes (Martin, 2000). According to Bate and Boateng (2007), counterfeit medicine is a large threat to global health, and there is no area in the world that is not affected. While there are many legal and reputable on-line pharmacies, many illegal ones exist, assisted by potential drug traffickers who use the web in an attempt to undermine the existing prescription drug system (International

Internet, 2005). These illegal sites target the sick, needy, and elderly suffering from disease or addiction (International Internet, 2005).

From the Risks of Self-Diagnoses to the Dangers Self-Treatment

Selling drugs on the Internet has become a big business, as prescription medications are used to help millions of Americans daily (International Internet, 2005). The medications are made available for consumer purchase and can be obtained through on-line pharmacies even without a prescription. In 2005 alone, more than 4,600 illegal Internet pharmacies that were run by a ring of people from different locations in the United States were shut down by federal drug investigators (Tedeschi, 2005).

Identifying fraudulent sites is not easy for many consumers. Good html and design skills make it easy for unlicensed drug sellers to pass themselves off as being reputable licensed providers (Tedeschi, 2005). Access to medication without a prescription has never been easier. Many on-line pharmacies provide short patient symptom and general health questionnaires with answers already checked off and use these as secure and safe on-line diagnoses (Tedeschi, 2005) from purportedly licensed physicians in order to generate prescriptions. The consumer is led to believe that the completed questionnaires were transmitted to a legitimate and licensed physician, who would then generate a prescription and send it to a licensed pharmacist (Tedeschi, 2005). What happens in reality is that the operators of the rogue sites fill the orders themselves without any involvement of a doctor or pharmacist or send these orders to an illegal wholesaler in return for payment in the form of commission (Tedeschi, 2005).

Two types of on-line pharmacies exist: those that simply dispense drugs, and those that both dispense and prescribe (Sweet, 2001). The implications and risks to

patients using such on-line pharmacies are still largely underestimated, but are expected to continue to cause severe illness and death (Bate & Boateng, 2007). The online pharmacies that dispense drugs require that a user create an account, provide credit card and insurance information, and submit a prescription from their doctor. In most cases, dispensing pharmacies are legitimate and provide a convenience for the patient. The online pharmacies that prescribe and dispense medications do so having a patient respond to a questionnaire. The pharmaceutical websites present a risk for patients who self-diagnose and self-treat. Patients run the risk of receiving medications that are inappropriately prescribed or may be dangerous because of interactions with other drugs (Sweet, 2001).

What is most dangerous is the foreign websites that do not require patients to have a prescription or to fill out a questionnaire. Many of these sites are currently targeted by the FDA (Sweet, 2001). Additionally, the sites and drugs they ship are not regulated by the FDA and are potentially harmful to consumers because they can be counterfeit, expired, or contaminated (Sweet, 2001). Based on the health and safety risks, as well as financial implications of use, the U.S. government is paying close attention to the use and availability of on-line distribution of prescription drugs (Sweet, 2001).

Web-Based Health Information and Regulatory Activity

As the use of the Internet for health information becomes more widespread, so does the risk that growing numbers of health consumers will stop or reduce how often they consult a physician, causing a decrease in the overall consumer quality of care (Paidakula, 2006). Patient safety is an important issue for lobbyists, special interest groups, and political action groups. Groups such as the American Medical Association's

(AMA) (2007) House of Delegates and Council on Science and Public Health have been lobbying patient safety issues since their inception. Other special interest groups such as the Society of Gastroenterology Nurses and Associates (2007) have supported legislative efforts to improve the health care environment for patients and have even formed political action groups to raise money to do so.

While the health advocacy organizations are countless and can have a profound impact on regulating the validity and accuracy of web-based health-related information to ensure patient safety and health outcomes, no formal actions have been taken to date to do so. While not specifically related to web-based dissemination, the group that has come closest to doing anything related to regulating the content of patient education is the National Consumers League (NCL) (2005). A board member of the National Council on Patient Education and Information (NCPIE), the National Consumers League is comprised of more than 125 organizations responsible for improving communication and information about drug use by health care professionals and consumers (NCL, 2005).

Conclusions

The use of information systems in health care started in the mid 1950s but became much more popular in the 1990s with the mass availability of personal computers and the use of the Internet (Polsson, 2008; Thede, 2007). With the rise of the Internet and the next generation of affordable, fast, and interactive PCs came the health care technology explosion (Thede, 2007). Technology such as the Internet has enabled doctors to simplify the practice of medicine, talk to patients, gain drug information at the tips of their fingers, and even submit an electronic prescription to a local pharmacy on behalf of a patient

(Thede, 2007). According to Thede, the Internet has also provided fast access to health-related information to consumers and patients alike.

Currently, there are more than 40 million Americans who are uninsured either because they are unemployed or are unable to afford coverage and do not have assistance from employers or the government for affording coverage (Frank, 2007; Padamsee, 2006). According to Buckley (2009), the largest group of uninsured people in the nation is a group in their 20s, estimated to be more than 13.2 million in 2007. These young invincibles do not have insurance because of very high premiums and because their age makes them to feel invincible (Buckley, 2009). For the uninsured, health care is very limited and often times not a viable option. They can access health care only if they pay for it themselves, obtain it from free public clinics, or attempt to obtain it as charitable care (Padamsee, 2006). Alternatively, there is the Internet.

Many people choose to use Internet resources such as WebMD to play the role of a physician (Buckley, 2009); they self-diagnose and self-treat. Consumers who are without health insurance coverage have a strong tendency to use the Internet for health information (Budorf et al., 2003). They self-diagnose and self-medicate using potentially dangerous on-line pharmacies (Colliver, 2008), yet lack the knowledge to make informed decisions (Hardey, 1999; Lorence & Abraham, 2006). Regardless of the risks imposed by the Internet as a self-treatment tool, Americans seem to be willing to take that risk due to the lack of access and the unavailability of health care and prescription drug coverage (Colliver, 2008).

The growing use of medical websites to obtain health care (Martin, 2000) offers varying benefits to consumers that include convenience and access. The health care

revolution has also increased concerns that consumers may expose themselves to inaccurate information or endangerment, particularly as a result of sites used for fraudulent purposes (Martin, 2000). According to Bate and Boateng (2007), counterfeit medicine is a major threat to global health and is a threat to consumers who make the decision to self-treat after an initial web-based self-diagnosis

Summary

Consumers have a propensity towards self-diagnosis because of ease, privacy, and flexibility (Lewis, 2001) of finding diagnostic information within personal settings.

According to Lewis (2001), consumers favor the option of self-testing and diagnosis because the options are viewed as being more convenient and less expensive than visiting a doctor's office. The self-diagnostic and monitoring devices market has been booming since the 1970s when the first at-home pregnancy kit was released (Lewis, 2001). The heavy utilization of home self-diagnostic devices has raised red flags with health care professionals (Lewis, 2001). With the recent shift to the Internet as a cost-effective and readily accessible tool for medical information and self-diagnosis, more patients are becoming actively involved in their own health care management (Levy & Strombeck, 2002).

The Internet as an information source for medical and health-related information may pose a risk (Lorence & Abraham, 2006) to consumers who may rely on such information to self-diagnose and self-medicate (Herrick, 2005). These consumers do not have the knowledge or training to make informed decisions about their health or successfully diagnose and treat themselves (Hardey, 1999; Lorence & Abraham, 2006).

Studies have shown that consumers are unable to accurately understand their physical signs and symptoms and subsequently properly report on them (Xu et al., 2004).

A growing number of consumers are using web-based assessment tools for self-diagnosis and treatment, while not seeking help or advice from a doctor after the diagnosis (Kerka, 2003). As a result, consumers may often choose to self-medicate using over-the-counter medications. This can result in a disruption of the patient/physician relationship; only one out of 40 self-diagnoses results in a medical consultation with a physician (Herrick, 2005). As the use of the Internet for health information continues to become more widespread, the risk to the overall consumer quality of care increases (Paidakula, 2006) because of incorrect or misleading information (Risk & Dzenowagis, 2001). Another risk is that a growing numbers of health consumers will seek professional medical advice less often or not at all (Paidakula, 2006).

As Internet-empowered consumers become more actively engaged in managing their health care by proactively becoming involved in self-diagnosis, testing, and self-medicating, there are negative implications and dangers of self-treatment (Levy & Strombeck, 2002). There are positive implications as well. Levy and Strombeck (2002) suggested that the Internet, if used properly, can help reduce the cost of health care and has already transformed standard health care practices and health education, enabling the quick facilitation and exchange of large amounts of information to diverse audiences and communities across the globe.

Predicting and evaluating a consumer's ability to properly use Internet-based health tools and the overall safety, effectiveness, and efficacy of their actions is difficult to predict (Levy & Strombeck, 2002). As Internet-based health assessment and

management tools continue to develop globally, it is critical that medical leaders better understand the implications of such tools and their effect on consumer health behaviors. Leaders also must understand the possible outcomes so they can ensure a safe and quality health care environment. Chapter 3 will present the methodology of the current study, which will include the research method used, the design appropriateness, the study population, and the data collection procedures and rationale. The identification of data analyses that was performed will also be discussed.

CHAPTER 3: METHODOLOGY

The purpose of the current qualitative descriptive research study using a Delphi design was to explore expert opinions about future ramifications of web-based health assessment tools. The exploration included potential health benefits and risks that such tools could have on patient health behaviors and health outcomes. Additionally, the study was conducted to explore recommendations for best practices in incorporating web-based health assessment tools into quality health care and continuing health management.

To understand how to ensure the needs of health consumers are met, a panel of experts in health care participated in a qualitative Delphi study to reach a consensus on potential health benefits and risks of web-based consumer health assessment tools as well as provide recommendations for safe and effective use of such tools. The main objective of the current Delphi method was to obtain the most reliable consensus from a group of health care experts using a series of surveys that had a controlled feedback mechanism (Simon, 2006). The panel of experts contributed expert opinions on the complex issues surrounding the ramifications of health outcomes resulting from the use of web-based health assessment tools based on a compilation of expert opinions and judgments that were of value to consumers, patients, care givers, health care professionals, and health care leaders.

Research Method and Design Appropriateness

Research Method

Research results and statistical data currently available on the effects of webbased health information and diagnostic tools on consumer health behaviors and subsequent outcomes could not be found. Further research is needed to explore how this information influences the health care decision-making of consumers and how it affects their health outcomes (Bundorf et al., 2006). Because the research topic of interest has not been extensively explored, the use of a quantitative study as an alternative was not appropriate. A quantitative framework tests hypotheses or tentative theories about a situation by requiring that behaviors and experiences of individuals be evaluated for statistical significance (Quaglia, 2006). Creswell (2005) believed that qualitative research works well when the purpose is to learn from participants through exploration because there is little information available through literature review and not all variables are known that are related to the research problem.

The Delphi study was most appropriate for the current research because the design enables theories to be developed using expert opinions and recommendations for a new situation where none existed before. Exploratory theories can be developed as a result using this method (Simon & Francis, 2004). A systematic method for obtaining, exchanging, and developing an informed opinion was achieved by surveying a panel of primary care physician experts working in the health care field for five or more years (Simon, 2006). Consensus-based forecasting is a vital aspect in the formulation of future plans and policies needed to ensure safe and effective use of web-based health information and tools and helps define the future direction for optimal design and utilization of such tools (Ono & Wedemeyer, 1996). Health care leaders and government policymakers may use the study findings to understand better the ramifications of web-based health assessment tools in the United States during a time when health care availability is an issue. Study findings may provide support to create effective plans to maximize effectiveness of Internet tools while addressing potential threats and risks.

Research Design

The current qualitative descriptive research study was conducted using a Delphi method to obtain the opinions of health care experts through gathering, exchanging, and developing an informed opinion (Simon, 2006). The selection of the most appropriate research design was guided by de Meyrick (2003), Grisham (2008), Creswell (2005), and Madill and Gough (2008). These researchers laid the groundwork for selecting a qualitative descriptive Delphi study design over a quantitative Delphi design to understand potential opportunities and threats of web-based health tools and identify best practices. As research on the specific area of focus had not been conducted, a Delphi method designed to build a consensus of expert opinions was best suited for the study (Creswell, 2005).

The Delphi is only one of many approaches that could have been used to achieve the purposes of the current study. The preferred study design would be the one that is most appropriate for gathering and exploring informed insights about the complex issues around Internet health tools and possible health behaviors and outcomes for consumers (Grisham, 2008). According to de Meyrick (2003), a Delphi study is best suited for complex health-related issues because it utilizes a small group of health care experts to gain knowledge and opinions that could help guide best practices related to the issue of concern.

The Delphi approach was a systematic approach for gathering and formulating an informed opinion about the ramifications of web-based health assessment tools and recommendations for best practices by surveying a panel of health care experts around the nation (Linstone & Turoff, 2002; Loo, 2002). Delphi is an established technique for

examining and analyzing a potential future issue and forecasting outcomes and recommended solutions using a phased approach (Ono & Wedemeyer, 1996). The Delphi approach allowed a group of experts to explore, discuss, and reach consensus on a complex problem by bringing together a panel of selected experts who represented a broad spectrum of opinion. The Delphi approach included conducting surveys with the panel using a series of structured questionnaires and feedback reports. The Delphi method consists of several phases.

The first phase is intended to explore the subject matter studied. In phase one, each panel expert provides insights into the questions about the issue. The second phase allows panelists to agree or disagree and reach a group consensus on specific topics and areas of focus using terms of importance and feasibility. The closing phase is the final evaluation of the panel's responses.

The design for the current study was the best choice for exploring expert opinions to gain consensus and was both a reliable and valid method to accomplish the goals of the study through its phased approach (Linstone & Turoff, 2002; Loo, 2002; Simon, 2006). The Delphi method was suitable to the current study because it is the most appropriate and systematic approach for forecasting the future and exploring, discussing, and reaching consensus on a complex problem through a broad spectrum of opinion through a set of structured questionnaires and feedback reports (Linstone & Turoff, 2002; Ono & Wedemeyer, 1996). The preferred method used a set of controlled questions that was sent to a panel of physician experts, who answered these questions and provide their confidence level weighting for each. Once responses were received and compiled, the results were rank ordered by participant responses and sent to the panel of experts for a

second round of questions and responses. The study continued until consensus was reached and no new information could have been gathered from the process (Mullen, 2003).

The Delphi method involves reiterative probing in which data are gathered by using a series of questionnaires (which included both closed- and open-ended questions) delivered to a panel of geographically dispersed health care experts whose viewpoints were summarized statistically and presented back for additional insight (Mullen, 2003). In the first questionnaire, the panel members were asked to respond to broad questions defining their personal information, explaining their experience and understanding of the Internet, and describing possible problems, potential solutions and recommendations, and predictions for the future concerning Internet health sites. Each subsequent questionnaire was built on responses to the preceding questionnaire, ending when consensus was achieved among the participants and when the study objectives were achieved (Mullen, 2003). Three rounds of questioning occurred.

Population

The credibility of the Delphi study comes from "its ability to draw on expertise [through its] purposeful selection of experts for inclusion to the panel" (Hanafin, 2004, p. 19) who have the desire and capability to provide legitimate input on the topic that is being examined without the potential for bias. The successful completion of the current Delphi study relied on the experiences and opinions of health care experts on issues related to the Internet and its effects on consumer health behaviors and outcomes (Hanafin, 2004). The selection of each participant was not random; each selected participant was recognized for his or her knowledge and experience in this area —

supporting the selection of the Delphi research method to gain access to expert opinion for the study (Cook & Frigstad, 1997). To ensure study validity, the panel consisted of a sample of 26 physician experts who have five or more years of practical work experience in general or specialty medicine (Shaw, Southwood, & McDonagh, 2004).

Sampling

A sampling number of 26 health care experts was determined to ensure study validity as proposed by Shaw, Southwood, and McDonagh (2004). Experts were located in the United States and were identified and selected for participation using web-based social networking site LinkedIn. Additional recruitment assistance came from personal referrals provided by participating or invited physicians. All chosen participants were licensed to practice medicine and had an established medical practice and practical, working experience with the Internet, including patients who used the Internet as a tool as a source for medical information gathering, diagnosis, and treatment.

Selection criteria for the pilot participants were based on the qualifications of the individuals selected. The invitation letter (see Appendix A) sent to participants included a qualifying declaration stating that only practicing physicians meeting outlined criteria were able to participate in the study. Specifically, this criteria included the number of years in practice; the number of patients seen per day; and experience in interacting with patients who had used the Internet as a source for medical information seeking, self-diagnosis, and/or self-treatment.

Selection criteria for the expert panel included that the panel members had more than five years working experience as a practicing physician and a patient base that was greater than or equivalent to 10 patients per day. To qualify, prospective participants

must have had experience with patients who used the Internet for health-related activities. To avoid bias, participants were not selected solely because they are readily available, personally known by the researcher, or only meet partial selection criteria (Hanafin, 2004).

As part of the pilot in preparation for the final study, the sample for this study was identified, invited, and recruited through the use of LinkedIn as well as through referrals from physicians who had agreed to participate in the final study (potential snowballing effect). LinkedIn is a professional network website that has more than 75,000 active physicians as members. LinkedIn allows members to connect to one another electronically based on their shared networks or interest groups and allows for the sharing of information and ideas.

Upon approval of the current study, a pilot study was conducted. The pilot panel consisted of five physician experts who tested the predetermined criteria to be applied to the members of the study panel. Each pilot participant had an understanding of the topic and purpose of the current study and had a stake in the outcome (Creswell, 2005). Selection criteria for the pilot participants were based on the qualifications of the individuals selected. The invitation letter (see Appendix A) sent to Pilot participants included a qualifying declaration stating that only practicing physicians meeting outlined criteria were able to participate in the study. Specifically, this criteria included the number of years in practice, the number of patients seen per day, and experience in interacting with patients who had used the Internet as a source for medical information seeking, self-diagnosis, and/or self-treatment.

Selection criteria for the expert panel included that the panel members had more than five years working experience as a practicing physician and a patient base that was at least 10 patients per day. To qualify, prospective participants must have also had experience with patients who used the Internet for health-related activities. To avoid bias, (Hanafin, 2004) select participants were not selected based on convenience or acquaintance with the researcher. Prospective participants who did not meet all selection criteria were also not selected.

Informed Consent

Confidentiality is a critical aspect of the Delphi technique because the identification of the participants is directly linked to the responses in the questionnaire (Hanafin, 2004). Ethical issues around privacy, consent, and confidentiality must be considered. Informed consent from each participant at every stage should be achieved, and information that is provided back from the study by each participant must not reveal the identity of the participant (Hanafin, 2004). Each potential study participant was ensured that his or her responses would remain anonymous and participation was confidential.

An email explaining the purpose of the current study and the study confidentiality was sent to each prospective participant (see Appendix A). A follow-up email with an attached informed consent document (see Appendix B) was sent to pilot participants and study participants only. This email included a request that the informed consent form be signed and mailed back to the researcher. Signing the form confirmed that the study participant understood the factors of the study and was a willing participant. The data collection did not begin until the original signed form was signed and returned.

Each participant was assigned a unique identification code number. Identifying information that ties the code to the participant was stored in an electronic file secured by a password and only available to the researcher. Efforts were made to ensure the privacy of each participant by maintaining confidentiality of participants and the anonymity of their responses (Hanafin, 2004). Survey questions were constructed in such a way to ensure that responses would not reveal the identity of participants. Names and affiliations of participants were also not linked to questionnaire responses. Instead, survey responses were tracked via the unique identifier (number) that was randomly assigned to each participant at the beginning of the study (Hanafin, 2004). Completed surveys were classified using the unique identifier code, were stored on a removable disk drive for a period of three years, and will then be destroyed.

Data Collection

The Delphi study used various means of data collection (Creswell, 2000). First, the questionnaire was based on a set of criteria used to identify associated risk factors, opportunities, and best practices of using the Internet for health-related activities by consumers. Second, the study allowed each panelist to provide input into the creation of criteria, which was then rated using a 5-point Likert-type scale questionnaire. Finally, the panelists were provided the ability to reach consensus or explain their deviation from the group in relation to the overall perception.

Collection

The Delphi method used in the current study consisted of three rounds of surveys through which a group of de-identified experts was asked to respond to a series of surveys in an effort to come to consensus without direct debate (Linstone & Turoff, 2002;

Simon, 2006). To gain insight into the expertise and experiences of experts, the Delphi method included collecting views and opinions using reiterative probing through which data were gathered by using a series of questionnaires delivered to a panel of geographically dispersed health care experts. Panelists' viewpoints were then summarized statistically and presented back for additional insight (Hanafin, 2004). Three rounds of questioning were conducted, which allowed participants to review and revise their opinion, positions, and judgments throughout the process (Hanafin, 2004). *Feedback*

The feedback from the first questionnaire (see Appendix C) provided the initial insight into the panel members' experience and understanding of the Internet and its use by consumers for health information and health outcomes and described possible problems, potential solutions and recommendations, and predictions for the future. Each subsequent set of responses to further questionnaires built on the insights from the preceding ones. Responses to subsequent questionnaires generated a broad range of alternative insights and provide consensus about possible opportunities and risks associated with the Internet and consumer health.

Data Analysis

In the current Delphi study, data were gathered from participants during each survey round. A panel of health care professionals was asked to respond individually to a list of survey questions during the first round, using independent judgments and experiences about the discussed topics. In the third and final round, the panelists were asked to reconsider the questions that were outside the group mean and lacked consensus, and either revise those questions or provide a rationale. The qualitative data collected

from the three rounds of surveys were analyzed by the researcher using a computer software program for assistance.

According to Hanafin (2004), the Delphi study should be used to provide feedback to participants after every round and identify consensus when it has been reached. The data used for analysis in the current qualitative descriptive Delphi study were gathered from responses provided by the study participants to multiple rounds of survey questions (Hanafin, 2004). Data were presented using the median and mean scores as two main statistical measures in an effort "to provide an indication of the level of agreement amongst respondents" (de Villiers, de Villiers, & Kent, 2005, p. 641).

A growing number of consumers using the Internet continue to self-diagnose and decide which symptoms require consultation with medical personnel (Champion, 2007; Herrick, 2005; Tyson, 2000). According to Champion, the methods of data analysis in a Delphi study can vary based on the focus and purpose of the study, the number of total participants, and the question types used. Results of the data analysis in the current study could be used to generate suggestions, ideas, and recommendations to ensure a safe and quality health care environment based on the increasing proportion of patient/physician disruptions (Herrick, 2005).

Specific observations were made based on the responses to survey questions and consensus building in an effort to draw conclusions related to the broader phenomenon (Leedy & Ormrod, 2001). The first round of questions was unstructured with the purpose of defining specific themes to be used in the second round for follow-up. The first round allowed participants to share their autonomous views about the topic of discussion. Upon

completion of the first unstructured survey, content analysis of responses was conducted to identify formulated themes.

The analysis of responses from the first round was used to create a structured survey as the basis for the remaining rounds (see Appendix D). Data collected from subsequent rounds were qualitative in nature, as they continued to be based on the feelings, experiences, and values of the responding physicians. Second and third round responses represented a combination of panelist responses, which were "analyzed and calculated with mean and median scores using ranking or rating techniques with a Likert-type scale" (Champion, 2007, p. 95). The responses to structured questions asked in the second survey used a 5-point Likert-type measurement scale as a rating mechanism for analysis of consensus and the formulation of new questions for the third round (Grobbelaar, 2006). Responses to the second and third questionnaires were calculated using a mean score to identify consensus. In the third round, the panelists were asked to reconsider the questions that lacked consensus, and either revise their answers or provide a rationale. An indication of how each participant scored in relation to the cumulative response was provided to each participant.

Consensus is critical in a Delphi study and is defined by de Villiers et al. (2005, p. 639) as "a gathering around median responses with minimal divergence." For the purpose of the current study, consensus is defined when 75% or more of the responding experts are in agreement with a particular belief or statement represented by a survey question (de Villiers et al., 2005). To ensure that lack of consensus is not hidden, a bi-modal distribution was used as a way of demonstrating the diffusion of the score (Champion, 2007). For responses to questions that lacked consensus, a third round questionnaire was

used to enable panelists to reconsider their responses and make appropriate revisions to scores (Champion, 2007).

All data resulting from the surveys were initially captured and analyzed using Microsoft Excel, which enabled the mean, median, and standard deviation to be measured and demonstrated. The analysis provided information based on the data that were collected from participants during each round of the study. The software tool supported the analysis by providing the ability to ensure that the data could be viewed and assessed in detail and with the highest level of accuracy. In addition to capturing and analyzing the data, the tool also has the capabilities to allow for memos and annotations to be recorded as well as theme categorization – both of which are necessary for the success of data analysis in the study (Champion, 2007).

Validity and Reliability

According to Leedy and Ormrod (2001), all research methodologies must be valid in their approach. Specifically, they must be accurate, credible, and meaningful. Validity is used to determine whether the research conducted, along with the research instruments used, measured what it was intended to measure and measured the truthfulness of the results (Golafshani, 2003). In health care medical management, validity of survey questions and responses is critical to ensure that the indicators used reflect the outcomes identified and should be based on scientific evidence (American Society of Anesthesiologists, 2005).

The Delphi technique is based on the premise that the experts have the best insights into the future of a particular issue researched. The validity of the Delphi study depends on the expertise of the participating panel of experts (Ludwig & Starr, 2005).

According to Shaw, Southwood, and McDonagh (2004), the Delphi method must consist of a panel of experts in order to maximize the study's validity. While there are no specific standards that define characteristics of experts, the views of a small panel of carefully chosen participants can provide representative, valid insight into a particular area of study (Shaw, Southwood, & McDonagh 2004).

Further validity was gained for the Delphi method through the use of a pilot study to validate question design and appropriateness using five physician experts as well as ensuring an appropriate number of participants. The validity and reliability of the study and its results increase when a group of participants is larger than 15 (Shaw, Southwood, & McDonagh, 2004). The study included an initial panel of 26 experts participating in round 1, 24 experts continuing on to round 2, and 22 of those experts completing round 3, which was considered appropriate to uncover valid and reliable response patterns (Shaw, Southwood, & McDonagh, 2004).

Validity of the study was established through survey questions presented to the health care professionals in each phase of the Delphi study and the subsequent responses provided. Evaluating the reliability of the results was based on the consistency of the results among the three surveys (Golafshani, 2003). To ensure reliable data, responses were monitored to establish the linkage between responses in each phase (American Society of Anesthesiologists, 2005). The Delphi study provided an explanation for the results (internal validity) and showed that the results were generalizable to a larger population (external validity) (Leedy & Ormrod, 2001).

Internal Reliability

According to Leedy and Ormrod (2001), internal validity enables a researcher to accurately conclude the relationship between the cause and effect within a study. The initial study design and the succeeding data were used to deduce this relationship, using input from the participants to the various waves of surveys conducted during both the pilot and final study.

External Reliability

External validity will enable the researcher to understand how the study results apply in a non-controlled real-life setting (Leedy & Ormrod, 2001). The selection of participants in both the pilot and final study played an important role in the external validation of the current study. To ensure external validity, the selection of the representative sample denoted experts who were not biased, were open, and were impartial in rationale and given feedback (Leedy & Ormrod, 2001).

Summary

The current descriptive qualitative study using a Delphi technique was conducted to investigate the future ramifications of Internet-based health tools and their effect on consumer health behaviors and outcomes. With consumer access expanding to medical information once only available to physicians (Herrick, 2005), there is a need to uncover existing opportunities and risks associated with using web-based health assessment tools. Equally necessary is development of a recommended plan that incorporates into quality health management the opinions of health care experts regarding the current and future use of such tools by adult consumers. According to de Meyrick (2003), a Delphi study is best suited for such complex health-related issues as it utilizes a small group of health

care experts to gain knowledge and opinions that can help guide best practices related to the issue of concern.

Creswell (2005) believed the use of such explorative qualitative research will work well when little information is available through literature review and not all variables related to the research problem are known. The Delphi method was the most appropriate technique for the current study, as the method allows a group of experts to explore, discuss, and reach consensus on this complex problem (Linstone & Turoff, 2002). The Delphi method brought together a panel of selected experts who represented a broad spectrum of opinion and enabled surveys to be conducted with the panel using structured questionnaires and feedback reports (Loo, 2002).

The findings and results of the study are presented in chapter 4 will. Chapter 5 will provide study conclusions and implications as well as recommendations of what health care leaders, policy makers, and consumers can do to incorporate the use of Internet-based self-assessment tools into quality health management and ensure optimal patient/physician interactions.

CHAPTER 4: RESULTS

The primary purpose of the current qualitative study was to explore expert opinions, values, perceptions, and feelings of health care providers about future ramifications of web-based health assessment tools including potential health benefits and risks that such tools can have on patient health behaviors and health outcomes (Qualitative Research Consultants Association, 2007). Additionally, the study was conducted to explore recommendations for best practices in incorporating web-based health assessment tools into quality health care and continuing health management. To understand how to ensure the needs of health consumers are met, a panel of experts in health care participated in a qualitative Delphi study in which they relied on their experiences, values, perceptions, and feelings to reach a consensus on potential health benefits and risks of web-based consumer health assessment tools, and provided recommendations for safe and effective use of such tools.

Chapters 1, 2, and 3 presented the theoretical foundation and methodology of the qualitative Delphi research study, as well as the research questions. Chapter 4 presents the survey results from the panel of experts in medical practice. The Delphi technique allowed the experts to address the need for effective health care practices that will ensure a safe and quality health care environment. The need for such practices is the result of an increasing proportion of patient/physician disruptions (Herrick, 2005). These include a growing number of consumers using the Internet for health information and self-diagnosis and identification of which symptoms require consultations with medical personnel (Herrick, 2005; Tyson, 2000).

While the growing availability and use of Internet health tools can benefit the global expansion of consumer awareness, the Internet tools may expand the chance of consumer health risks associated with a breakdown in the patient/physician relationship because of the growing number of consumers not seeking help or advice of a physician after self-diagnosis (Kerka, 2003). Medical leaders cannot ensure a safe and quality health care environment based on the increasing proportion of patient/physician disruptions (Herrick, 2005). A growing number of consumers use the Internet to self-diagnose and decide which symptoms require consultations with medical personnel (Herrick, 2005; Tyson, 2000). Specifically, because health-related websites are expanding consumer access to medical information once only available to physicians (Herrick, 2005), there is a need to develop a recommended plan that incorporates the use of Internet-based self-assessment tools into quality health management.

To understand how to ensure the needs of health consumers, the Delphi technique allowed the experts to address potential health benefits and risks of web-based consumer health assessment tools as well as provide recommendations for safe and effective use of such tools. The findings from the panel of medical experts provide the basis of the framework to support a method to obtain a reliable consensus through a series of thorough questionnaires with opinion feedback (Champion, 2007). To understand how to ensure the needs of health consumers are met, the goal of the current study was to present a framework to investigate the consensus of medical experts on the future ramifications of web-based health assessment tools on consumers by exploring the opinions of health care professionals on the potential health benefits and risks that such tools could have on patient health behaviors and health outcomes through a Delphi method of surveys. A

panel of experts in health care participating in the qualitative Delphi study was asked to reach a consensus on potential health benefits and risks of web-based consumer health assessment tools as well as provide recommendations for safe and effective use of such tools.

Study results may aid in planning for long-term interests and advocacy on the complex issues surrounding the ramifications of health outcomes resulting from the use of web-based health assessment tools. The study findings and recommendations are based on a compilation of expert opinions and judgments that were of value to consumers, patients, care givers, health care professionals, and health care leaders. Findings and recommendations can serve as a foundation for health care executives and leaders of the country to understand better how the Internet is being used for health care related issues and the potential health risks, dangers, and outcomes that such utilization can have on the nation.

As the use of the Internet for health information becomes more widespread, risk to the overall consumer quality of care increases (Paidakula, 2006) resulting from incorrect or misleading information (Risk & Dzenowagis, 2001) and a growing number of health consumers who will stop consulting physicians (Paidakula, 2006). Predicting and evaluating the overall safety, effectiveness, and efficacy of consumer Internet use for health information is difficult, and further research is needed to explore how this information influences the health care decision-making of consumers and how it affects their health outcomes (Levy & Strombeck, 2002; Bundorf et al., 2006). The results of the current study inform the discovery of flaws and strengths in the current system, which could ultimately lead to the transformation and optimal use of Internet-based health

information and tools. The predictions on how such tools could positively and negatively affect the stakeholders may enable future studies in the design of action plans and changes that need to be made to maximize the strengths of the Internet while minimizing the weaknesses. The contributions of the study could lead to future global studies and leadership initiatives to secure the way health information is managed through the transformational power of open communication, trust, and support of consumers, health care professionals, and world-wide leaders.

A pilot study was conducted to assess the level of reliability and usability of the survey instrument. The following research questions were developed to explore the ramifications of web-based health information and assessment tools on consumer health behaviors and outcomes. These guiding questions served as an inquiry framework to explore and generate thoughts related to the benefits and risks of web-based health tools and how such tools can be used to achieve optimal consumer health behaviors and outcomes, while minimizing risks and weaknesses.

- 1. How has the Internet changed health care?
- 2. Can self-help and health information websites influence consumer health behaviors and health outcomes?
- 3. In your experience, what have been some health risks associated with the use of self-help and health information websites by patients, consumers, and caregivers?
- 4. In your experience, what have been the benefits of such tools?
- 5. Should the use of the Internet tools and websites be incorporated into health care practices?

6. How could health professionals including doctors, nurses, pharmacists, and even health librarians be integrated into the web-based health information model to support consumers in need?

Data were collected to answer the questions through a Delphi technique of inquiry in three rounds of surveys. The expert participants in both the pilot study and the Delphi study remained anonymous to one another throughout the study. Chapter 4 presents the findings of the data collected.

To avoid bias, participants were not selected solely because they were readily available, personally known by the researcher, or only met partial selection criteria (Hanafin, 2004). Potential panelists were initially selected based on their professional designation on the social media site, LinkedIn. The criteria for panelist inclusion was based on the physician's willingness to participate as well as the number of years in practice; the number of patients seen per day, and their experience in interacting with patients who use or have used the Internet as a source for medical information seeking, self-diagnosis, and/or self-treatment. Inclusion criteria were that each panelist must have more than five years experience working as a practicing physician, treat more than 10 patients per day, and have experience with patients who use the Internet for health-related activities. Table 1 depicts a summary of the demographics of the 26 participants who represented a highly qualified, diverse, and knowledgeable panel of health care experts.

Table 1

Demographics of Study Participants

| Demographic | n |
|---------------------------|----|
| Gender | |
| Male | 23 |
| Female | 3 |
| Practice Type | |
| Primary Care | 14 |
| Specialty | 12 |
| Years practicing medicine | |
| 5 years or greater | 26 |

Each panelist was assigned a number for data collection purposes (P1, P2, P3, etc.) that was assigned to them in numerical order. Next, the potential panelists were informed of the study's time frame, which for Round 1 through 3 was in the range of two months. Forty-one experts quickly agreed to participate in the study and were sent the first questionnaire along with two-week turnaround deadline and an electronic consent form for completion. Within the given two-week time period, 26 completed responses and electronic informed consent forms (see Appendix B) were returned. Each communication for the three rounds in the Delphi study was individually emailed to each expert panel participant to ensure anonymity. Data for rounds 1 and 2 were collected through e-mail using a Microsoft Word-based survey. Round 3 was conducted using an

on-line survey tool. Rounds 1 (see Appendix C) and 2 (see Appendix D) surveys were completed and returned as an e-mail attachment.

The first round of the Delphi study included a cover letter clarifying the study's purpose, time frame, and directions, as well as the seed questions (see Appendix A). The second round included a cover letter with directions for rating statements produced from the first round of the study with a Likert-type rating scale of 1 to 5 (see Appendix D). Based on the responses and the data generated from round 2, the third round provided participants with round 2 survey results (see Appendix E) and directions and a web link to an on-line survey (see Appendix F) where panelists were asked to reconsider 11 statements that generated marginal consensus (between 64% and 75%) and either agree or disagree with the statements. Round 3 also gave panelists the opportunity to provide optional comments to their responses. The findings provided insight into the detailed responses addressing the research questions for the study.

A pilot study panel of five physician experts responded to open-ended questions regarding the ramifications of web-based health assessment tools on consumer health behaviors and health outcomes. The purpose of the pilot study was for the experts to validate and redirect the content of the questions for the instrument by reviewing and responding to the seed questions and to ensure the questions were stated clearly with minimal chance for misinterpretation. The collection and analysis of data for the study were performed using Microsoft Excel to find themes that were then used to develop the Likert-type scale questions for subsequent Delphi study rounds. A rigorous and careful exploration of the data was conducted and the findings are presented in the next section.

Results

The findings of the data collected from the panel of experts used to identify associated risk factors, opportunities, and best practices of using the Internet for health-related activities by consumers are presented herewith. To validate candidates who could participate in the study, a message clarifying the qualification requirements, the study's purpose, number of waves required in the participation, and the completion time frame were sent to a select group of 100 physicians from the AMA group on the professional social networking site LinkedIn. Additionally, each was asked to provide a contact email address if they were interested in participating in the study or to send the researcher a request to connect via LinkedIn (for the purposes of having contact information for interested physicians).

Of the 100 prospective participants contacted, only 14 did not meet the qualification criteria. Of the remaining 86 participants initially contacted, 41 qualified physicians responded within two weeks of initial contact, demonstrating interest in participating in the three rounds of the study. Each respondent had been a licensed, practicing physician, currently living in the United States, had five or more years experience practicing medicine, had experience with the web for accessing health information, and had experience with patients and caregivers who used the Internet for health information and diagnosis. Each of the 41 responding, qualified physicians was contacted by email, thanked for his or her response and welcomed into the study. A timeline of events and participation requirements was also included.

Of the 41 responding physicians, five were selected to participate in a pilot round to test the validity and usability of the seed questions constructed for the first round of the

study. The goal for the pilot study was to validate the design to improve results (Creswell, 2005). Through the pilot study conducted during August 2009, six questions and three sub-questions were framed from the initial research questions. The five participants received an email message welcoming them to the study and specifying that they had been selected to participate in a pilot. The email included directions for completing the pilot study. All five participants responded to the pilot survey within one week of receipt of the survey. Responses and feedback showed that the questions were concise and thorough and enabled the pilot study panelists to provide their insights on the key issues in the questions. The open-ended seed questions used in both the pilot study and the first round of the study were as follows:

- 1. How has the Internet changed health care?
- 2. Can self-help and health information websites influence consumer health behaviors and health outcomes? If yes, how?
- 3. In your experience, what have been some health risks associated with the use of self-help and health information websites by patients, consumers, and caregivers?
- 4. In your experience, what have been the benefits of such tools?
- 5. Should the use of the Internet tools and websites be incorporated into health care practices? If yes, why, and what types of strategies and policies can health leaders develop to ensure safe high-quality health care that incorporates the key resources and advantages available through the Internet?

6. How could health professionals including doctors, nurses, pharmacists, and even health librarians be integrated into the web-based health information model to support consumers in need?

Because the questions in the pilot study were validated by the panelists and had not been changed, the five pilot physician responses included in first round of the study. The first round of the Delphi study was sent by email to the remaining 36 physicians who had not participated in the pilot, which included an explanation and timeframe for the round 1 along with an attached survey (see Appendix C) consisting of six questions and an electronic informed consent form (see Appendix B) for completion. Of the total 41 participants, 21 additional responses were collected within the agreed-upon two-week timeframe and used in the round 1 analysis. The total number of participants in the first round of the study totaled 26, which included the five pilot panelists and 21 first round panelists.

The second round of Delphi study provided feedback to participants and developed reached by the 26 panelists through their responses to the six open-ended survey questions (Hanafin, 2004). Round 2 Likert-type questions were sent to each participant via a personalized email and contained the completion timeline and instructions for responding to the 48 statements produced from the first round of the study. These were formatted as Likert-type rating scales with a range of 1 to 5 corresponding to Strongly Disagree to Strongly Agree.

Based on the responses and the data generated from round 2, the third round provided participants with a synopsis of the consensus data, with directions asking panelists to reconsider 11 statements with marginal consensus in Round 2 (Hanafin,

2004). The format of round 3 gave panelists not only the opportunity to agree or disagree with the statements, but also to provide an open-ended comment to any statement if they wished. Of the 11 questions asked in round 3, only two did not result in consensus being reached.

Delphi Round 1

Responses to round 1 questions demonstrated a common set of responses that fell into the following 10 general themes, a few of which were commonly shared across multiple questions: Information Access; Consumer Engagement; Information Accuracy; Social Support; Empowerment; Patient/Physician Relationship; Self-Diagnosis; Financial Implications; Health Consequences; and Health Oversight. The documented themes were linked back to each question in round 1 as follows:

Themes associated with Question 1: How has the Internet changed health care?

- Information Access
- Information Accuracy

Themes associated with Question 2. Can self-help and health information websites influence consumer health behaviors and health outcomes?

- Consumer Engagement
- Empowerment
- Patient/physician relationship
- Social support

Themes associated with Question 3. In your experience, what have been some health risks associated with the use of self-help and health information websites by patients, consumers and caregivers?

- Self-Diagnosis
- Financial Implications
- Health Consequences

Themes associated with Question 4. In your experience, what have been the benefits of such tools?

- Empowerment
- Patient/physician relationship
- Social support

Themes associated with Question 5. Should the use of the Internet tools and websites be incorporated into health care practices?

- Health oversight
- Patient/physician relationship
- Financial implications

Themes associated with Question 6. How could health professionals including doctors, nurses, pharmacists and even health librarians be integrated into the webbased health information model to support consumers in need?

- Health oversight
- Financial implications

Themes were then used to construct the Likert-type questions in round 2 in an effort to obtain informed opinion and generate consensus vital in the formulation of future plans and policies needed to ensure safe and effective use of web-based health information and tools and helps define the future direction for optimal design and utilization of such tools.

Round 2 Survey Results

Response data from round 1 were analyzed and categorized by frequency or similarity of the response. During the second round of the modified Delphi study, the 26 experts were asked to rate 48 statements on a 5-point Likert-type scale (see Appendix D). Round 2 data were used to analyze the perceptions of participants based on how they rated each category (from most important to least important) from round 1 using a Likert-type scale, where rank was calculated for each and added thoughts or comments were captured (Hanafin, 2004). Of the 26 surveys sent out to survey participants, 24 completed and returned their questionnaires on time, one respondent did not respond to reminder emails, and one respondent requested to opt out of round 2.

In round 2, the themes collected from round 1 were rated on a five-point Likert-type scale used the following rating system: $1 = strongly \ disagree$, 2 = disagree, 3 = neutral, 4 = agree, and $5 = strongly \ agree$. All median scores from round 2 ranked at or above a 4 rating, which acted as an indicator of consensus. Tabulated response data to all 48 items comprising round 2 survey are reported in Appendix E.

As indicated in Appendix E, of the 48 Likert-type statements, 22 statements revealed a high degree of group consensus with 75%-100% consensus and a mean score of 4.0 or higher in 18 of the 22 statements. Eleven statements revealed marginal group consensus with 60-74% agreement and mean score above 3.5 (mid-way between neutral and agree) and were re-addressed in round 3 of the study. Fifteen statements generated low group consensus with <60% consensus and a mean score 3.5 or less. The low consensus statements were discarded from further investigation. The findings were

reported as examples of a unified opinion of no agreement in some instances where the lack of consensus is strong.

Round 3 included only the 11 statements that fell between 65% and 74% consensus, because at these statements depicted a moderate range of consensus (Champion, 2007) with mean scores above 3.5 and median scores of 4. The modified questions used in round 3, along with the comments that were provided by the experts, are displayed in Appendix F. Twenty-four panelists had the opportunity to re-evaluate statements from round 2 in a slightly reworded format. They were asked to either agree or disagree with the revised statements and were given the option to add comments as needed.

Only 22 of the 24 responded by the agreed-to timeline set forth in the instructions. Several panelists used the comments option to demonstrate their neutrality to the statement by neither agreeing nor disagreeing with the statement. Of the 11 questions, nine questions resulted in final group consensus, while two remained at marginal (see Table 2).

Table 2

Tabulated Results for Round 3 (n=22)

| Statement | Agree | Neither | Disagree | Consensus | Consensus | Mdn | Mean |
|-----------|-------|----------|----------|-----------|-----------|-----|------|
| | | Agree or | | Total | % | | |
| | | Disagree | | | | | |
| 1 | 19 | 2 | 1 | 19 | 86% | 3 | 2.83 |
| 2 | 21 | 0 | 1 | 21 | 95% | 3 | 2.9 |
| 3 | 21 | 0 | 1 | 21 | 95% | 3 | 2.9 |
| 4 | 19 | 0 | 3 | 19 | 86% | 3 | 2.74 |
| 5 | 14 | 0 | 8 | 14 | 64% | 3 | 2.39 |
| 6 | 18 | 0 | 4 | 18 | 82% | 3 | 2.65 |
| 7 | 16 | 0 | 6 | 16 | 73% | 3 | 2.57 |
| 8 | 19 | 0 | 3 | 19 | 86% | 3 | 2.74 |
| 9 | 20 | 2 | 0 | 20 | 91% | 3 | 2.91 |
| 10 | 20 | 0 | 2 | 20 | 91% | 3 | 2.82 |
| 11 | 22 | 0 | 0 | 22 | 100% | 3 | 3 |

Summary

The Delphi study was conducted to survey a sample of 26 health care experts in three rounds of surveys. An analysis of the collected specific bodies of knowledge utilized by successful experts was conducted. Data from the three rounds of the Delphi study were presented in chapter 4. The findings in the chapter summarize the consensus of the data collected from a panel of 26 health care experts in an online environment. The results, findings, and analysis from the Delphi study supported the study's goals. The results further validated the pilot study as a means to present a framework indicating trends towards safer and more effective means of engaging consumers and health care providers in web-based health care initiatives. The themes generated from round 1 and

evaluated in round 2 with added commentary in round 3 regarding risk factors, opportunities, and best practices of using the Internet for health-related activities by consumers and providers are reiterated here for clarity. The 10 themes generated in this study are Consumer Engagement, Information Access, Information Accuracy, Social Support, Empowerment, Patient/Physician Relationship, Self-Diagnosis, Financial Implications, Health Consequences, and Health Oversight.

The panel of experts in round 1 (n=26) had reached consensus that the Internet is a key source for the dissemination of health care information, patient empowerment, and social support. The experts unanimously expressed the need for greater physician involvement and regulatory oversight as a result of information inaccuracy and its effects on health consequences including potential misdiagnosis, self-treatment, and the unnecessary cost of care. Additionally, panelists shared many common values and beliefs regarding how the Internet has changed the patient/physician relationship.

The goal of the current study was to gain consensus from a panel of health care experts. Of the 48 questions asked in round 2, 22 statements generated a high level of consensus from the panel (n=24), with a 75%-100% agreement. Fifteen statements fell out of the minimum range, indicating less than 60% consensus and a mean score of 3.5 or less, and were eliminated from further consideration. Eleven statements generated a moderate range of consensus (Champion, 2007), with consensus between 60% and 74%, which is mean scores above 3.50 and median scores at 4 or 5. These were then reformulated in round 3, in which each expert was given the opportunity to reconsider his or her initial response in an agree—disagree format as well as in optional written responses to encourage further articulation and reach a higher consensus on statements.

Statements reevaluated in round 3 were to confirm current attitudes, beliefs, and thoughts on the benefits and risks that web-based health care information and assessment tools can have on consumer health behaviors and ultimately health outcomes. The panelists' open-ended responses served as a foundation for future best practices and to ensure better, more cost-effective consumer engagement, and health outcomes. In chapter 5 the findings are discussed and interpretations, implications, and final recommendations that may be important to health care providers, regulators, and leaders are provided.

CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS

Chapter 5 contains three sections. The first section provides an overview of the study. The second section is a discussion of the study results. The last section contains the summary and conclusion of the findings. It provides summarized suggestions that may be of benefit to health care professionals and medical leaders seeking to provide a safe and quality health care environment in view of an increasing proportion of patient/physician disruptions. The last section also includes a discussion of the implications and recommendations for further study.

Study Overview

Web-based health assessment tools can be defined as electronic interfaces that enable consumers to assess and diagnose medical conditions based on identified symptoms without the involvement of a health care professional (Demetrakakes, 2003). Potential health assessment sources include websites with automated modules that prompt users to enter information about symptoms, yielding possible conditions as a result; informational sites that describe symptoms associated with medical conditions; and consumer blogs that promote discussion of symptoms and conditions without the electronic presence or oversight of medical personnel. Tools such as these are common on the Internet, making self-diagnosis easier than ever before (Demetrakakes, 2003).

Only one out of 40 self-diagnoses results in a medical consult with a physician (Herrick, 2005). With a growing number of consumers using the Internet to self-diagnose and decide which symptoms require consultations with medical personnel, it becomes increasingly more difficult for medical leaders to ensure a safe and quality health care environment (Herrick, 2005; Tyson, 2000). According to Wallston (1997), health

behaviors constitute health-related actions impacting one's health status. Social learning theory states that the chance a person will engage in particular behaviors is a result of that person's anticipation that such actions will generate specific outcomes as well as the perceived value of the resulting reinforcement. Health-related websites continue to expand consumer access to medical information once only available to physicians (Herrick, 2005). As a result, there is a need to improve understanding of the ramifications that web-based health assessment tools have on consumer health behaviors and outcomes and develop a recommended plan that incorporates the use of such tools into quality health management.

A panel of health care experts was requested to participate in a qualitative Delphi study to reach a consensus on potential health benefits and risks of web-based consumer health assessment tools as well as provide recommendations for safe and effective use of such tools. The primary purpose of the study was to explore expert opinions, values, perceptions, and feelings of health care providers about future ramifications of web-based health assessment tools including potential health benefits and risks that such tools can have on patient health behaviors and health outcomes (Qualitative Research Consultants Association, 2007). Additionally, the study was conducted to explore recommendations for best practices in incorporating web-based health assessment tools into quality health insight, care, and continuing health management. To understand how to ensure the needs of health consumers are met, a panel of experts relied on their experiences, values, perceptions, and feelings to reach a consensus on potential health benefits and risks as well as provide recommendations for safe and effective use of such tools.

Results of the Study

The Delphi study brought together an anonymous panel of 26 selected experts for the first round of the study. Each participant was asked to respond to six open-ended questions representing a broad range of opinions on the issues and topic studied. Based on the responses, additional surveys were constructed using a series of questionnaires and feedback reports that are structured (Loo, 2002) using a multi-phase approach.

The second round of Delphi study provided feedback to participants and identified a series of new questions for consensus based on the 10 common themes derived from the initial survey questions (Hanafin, 2004). The questions were sent via email to each participant and were formatted as Likert-type rating scales with a range of 1 to 5 corresponding to Strongly Disagree to Strongly Agree. Of the initial 26 panelists, 24 responded within the timeframe guidelines set forth in the study instructions, while one did not respond in a timely manner and one asked to opt out of the study. Of the 48 questions asked, 22 questions revealed consensus with 75%-100% agreement. Ten questions revealed marginal consensus with 60-74% agreement and mean score above 3.5 (mid-way between neutral and agree, n=10). Sixteen questions showed minimal consensus with <60% agreement and mean score 3.5 or less (n=22).

Based on the responses and the data generated from round 2, the third round provided the 24 responding participants with a synopsis of the consensus data from round 2, with directions asking panelists to reconsider the 11 statements with marginal consensus (Hanafin, 2004). The format of round 3 gave panelists not only the opportunity to Agree or Disagree with the statements, but also to provide an open-ended comment to any statement. Of the 24 respondents questioned, 22 responded within a two-week

turnaround period set forth in the round 3 study guidelines. Of the 11 questions asked in round 3, only two did not reach final consensus.

The findings from the six round 1 open-ended questions allowed the development of themes that were the basis of statements to rate on a Likert-type scale in round 2. Further exploration allowed panelists in the study to reconsider previous ratings on statements and encouraged open-ended commentary in round 3. Results from each round of surveys were applied to each research question in the study to gain insight into expert opinions and experiences that can help guide best practices related to the issue of concern.

Study findings support the literature review and validate the importance of this study. With the recent shift to the Internet as a cost-effective and readily accessible tool for medical information and self-diagnosis, more patients are becoming actively involved in their own health care management (Levy & Strombeck, 2002). The growing use of medical websites to obtain health care offers varying benefits to consumers that include convenience and access (Martin, 2000). Distribution of medical information to millions of people in the United States (Rajendran, 2001) has been providing a significant opportunity for patients to become directly involved in their own health care (Forkner-Dunn, 2003). Rapid access to relevant health related information is highly beneficial as patients face challenges in making appointments to see their physicians and have limited time to discuss health care questions and concerns once they visit the office and finally see their physician (Tu & Cohen, 2008). The explosion of access to health-related information via the web can also enhance a consumer's understanding of his or her

condition, and can serve as a source of support through the use of social media technology such as patient health blogs (Potts & Wyatt, 2002).

Identifying fraudulent sites is not easy for many consumers (Tedeschi, 2005).

Because of the lack of regulations and massive amounts of low-quality information, the use of the web can result in misunderstanding or misinterpretation of findings as well as self misdiagnosis and mistreatment (Potts & Wyatt, 2002). As the use of the Internet for health information becomes more widespread, risk to the overall consumer quality of care increases (Paidakula, 2006) resulting from incorrect or misleading information (Risk & Dzenowagis, 2001) and a growing number of health consumers who will stop consulting physicians (Paidakula, 2006). Predicting and evaluating the overall safety, effectiveness, and efficacy of consumer Internet use for health information is difficult, and further research is needed to explore how this information influences the health care decision-making of consumers and how it affects their health outcomes.

Research Question 1

How has the Internet changed health care?

The first research question in round 1 asked expert panelists how the Internet had changed health care. Previous research demonstrated that the growing use of medical websites to obtain health care offers varying benefits to consumers that include convenience and access (Martin, 2000). Twenty-six physician experts responded to the open-ended question. From the analysis of their responses, information access emerged as a dominant theme among 25 of the 26 respondents (96%), as did information accuracy. Panelist 24 explained:

[The Internet] has placed a vast amount of resources literally at the fingertips of physicians, patients, care managers, health plans and other individuals engaged in health care. There are resources available to all aspects of the system. This rapid dissemination of information has the potential to improve health care through timely information about selected conditions and by education of consumers. It also has the potential to spread mis-information through a host of unregulated sites, so both the consumer and the physician must be aware of the quality of the information available and understand the sources.

In round 2, two Likert-type questions were constructed to ensure consensus with the two emerging themes. Of the 24 expert panelists who responded to round 2, 100% agreed the Internet provided consumers with faster access to health information. This confirms the finding of Herrick (2005) and Tyson (2000), which demonstrated that health-related websites have expanded consumer access to medical information that was once only available to physicians. The growing use of medical websites as real-time, interactive tools used for the provision of care services by consumers and patients offers consumers varying benefits that include convenience and access with limited boundaries (Martin, 2000). Ninety-six percent of the panelists also agreed that the Internet gave rapid access to clinical information. Expert 9 commented:

The Internet has enabled greater learning opportunities for physicians and patients. There are wonderful sites dedicated to delivering balanced, non-biased, and evidence-based data to clinicians such as UpToDate and the sites of the individual provider's specialty. All of the major specialty academies such as ACEP, AAFP, AAP, ACIM, ACS, and ACOG have clinical guidelines on their

sites. Physicians are also able to watch the latest lectures and stay up on CME. Many times it is difficult for physicians with a single provider practice to close shop for a full week at a time to go to a medical conference. The Internet allows them to get the education provided at the annual scientific assemblies without taking a week away from their patients. Patients can learn more about their disease processes. There are wonderful sites built by the American Heart and American Diabetes Associations that are great examples of productive content from which patients can learn. There are also tools that can be downloaded that help people keep up with data that affects their health, such as carbohydrate calculators and blood sugar logs that help with health care maintenance.

These findings confirm that the rapid distribution of medical information to millions of people in the United States (Rajendran, 2001) has been providing a significant opportunity for patients to become directly involved in their own health care (Forkner-Dunn, 2003). Between the years 2001 to 2007, America saw a substantial growth in the number of adults seeking information about a specific health issue or concern (Tu & Cohen, 2008). Such growing use of medical websites to obtain health care offers varying benefits to consumers that include convenience and access (Martin, 2000).

Round 2 responses demonstrated consensus that it is not easy for consumers and providers using the Internet for health information to distinguish fact from fiction. While the growing availability and use of Internet health tools can benefit the global expansion of consumer awareness and participatory medicine, these tools may also expand the chance of consumer health risks associated with information inaccuracy and the breakdown in the patient/physician relationship because of the growing number of

consumers not seeking help or advice of a physician after self-diagnosis (Kerka, 2003). Panelist 4 explained that the positive impacts include access to large volumes of health care information that can be used to access support groups, gain a better understanding of diseases or treatment options, or communicate with physicians. Conversely, the quality of information that is currently available is inconsistent and can contribute to consumers not seeking timely care, self-medicating, or seeking unnecessary care:

The quality of the information is variable, and consumers often interpret the information without any context. The impacts can range from a failure to seek care when needed, seeking unneeded care, or self-medicating with serious negative consequences.

General panelist consensus (92%) also suggested that advice found on the Internet such as patient support blogs can be wrong or misleading. As the use of the Internet for health information becomes more widespread, risk to the overall consumer quality of care increases resulting from incorrect or misleading information (Paidakula, 2006; Risk & Dzenowagis, 2001). Panelist 6 confirmed that the impact of consumer access to such false information is more negative than positive.

Unfortunately, the information that is "downloaded from the net," in most cases may be false information—anyone can claim to be "an expert" and offer advice on "diseases" they truly in fact know nothing about. Simply there is no good way to "Shepardize" the information the patient is reading and ultimately quoting as gospel to their physician, and there is a limited means to verify the credentials of the so-called "experts" reporting the information. Furthermore, even if the medical information is evidence-based, the reported illness specific facts, work-up

advised, differential diagnoses and treatment options available are most likely well beyond the patient's knowledge base, making caring for them as patients extremely difficult; forcing them to over-utilize services unnecessarily; making them demanding to the point that medical professionals are "forced" to order tests at the threat of litigation; and most importantly, making it more likely that they will be "misdiagnosed" through their own medical bias and tunnel vision.

Consumers making health decisions based solely on information they have obtained on the Internet can be put at risk. Because of the lack of regulations and massive amounts of low-quality information, the use of the web can result in misunderstanding or misinterpretation of findings as well as self misdiagnosis and mistreatment (Potts & Wyatt, 2002). Misleading web-based information can be posted by anyone claiming to be an expert, is not reviewed by a team of medical experts, and does not contain evidence-based knowledge. This finding is consistent with that of Tedeschi (2005), who believes that identifying fraudulent sites is also not easy for many consumers and that good html and design skills make it easy for anyone to look like a reputable provider. As the use of the Internet for health information becomes more widespread, risk to the general consumer quality of care increases (Paidakula, 2006) resulting from incorrect or misleading information (Risk & Dzenowagis, 2001). Panelist 22 stated:

We must remember that countless pages on the Internet are not peer-reviewed, and not evidence-based on sound medical knowledge. Literally, anyone can claim to be an expert in any given disease and recommend treatments. Many of these "recommended" treatments actually cause harm. Also, patients can delay actually seeking professional care following inappropriate advice from sources on the

Internet, thus causing a disease that could have been treated into a more advanced form that becomes incurable or untreatable. Additionally, people can purchase a multitude of pharmaceutical agents from many countries around the world at anytime without restriction. People can purchase experimental agents over the Internet that are not approved or studied and cause themselves serious harm. Also, fraud is rampant, and people can purchase what they think is medicine x and actually be taking a totally different drug, or possibly a placebo.

While access to inaccurate health information was cited as a key issue and concern for safe and effective care, the panelists did not agree that the Internet represented a disorganized repository of information and that the majority of such information was false or misleading. They did however suggest that such use can be viewed as a double-edge sword, and that patients who refer to the Internet to gather more information on a diagnosis after the physician consult can be at risk of finding misleading or conflicting information that can lead to behavioral or attitudinal issues (Hardey, 1999; Lorence & Abraham, 2006). Panelist 3 pointed out that:

Patients have turned to the Internet as a primary place for information when they are diagnosed with a certain medical condition or have a constellation of symptoms they want to find out more about. In my opinion, this is a double edge sword because there are many websites with either misleading or conflicting information that may give patients the wrong impression, diagnosis or attitude towards their health and the health care system in general.

Panelist 19 commented that web-based health resources have become commonplace and have replaced the multiple, often outdated reference materials of the

past. While access to such resources is useful to consumers and health care providers, Reviewer 20 referred to an increase of websites containing slanted viewpoints related to products and treatments, as well as a growth in utilization by those he refers to as the "worried well"

Access to information has increased, but more so by the "worried well" than by most others; an increased awareness of unusual diseases by potential sufferers (but usually by those who do not have the condition); a proliferation of websites offering medical information with a slanted point of view that favors a product or products (usually to sell them); huge numbers of unsubstantiated testimonials about the value of one treatment over another; enormous quantities of advertising; and some really quite useful information. The difficulty I see is that for a person with relatively little scientific background the ability to sort through the information and discern what is real or evidence-based vs. the "other" on the web is at best a haphazard endeavor.

With Internet self-diagnosis being so prominent in today's culture, a new term, cyberchondria, has been created to describe the phenomenon of patients who use the Internet as a self-diagnostic tool to uncover potentially life threatening conditions causing them to unnecessarily spend valuable health care dollars on emergency room visits or specialist assistance (Shrieves, 2009). The practice, according to Shrieves, has become quite common and confirms the findings of the present research.

While the Internet may pose risks, the explosion of access to health-related information via the web could also enhance a consumer's understanding of his or her

condition (Potts & Wyatt, 2002). Panelist 22 correlated information quality to the quality of the consult between the physician and patient.

My patients (or their parents) often present to me information retrieved from the Internet. Where the information is good, the patient already has expectations of what the diagnosis or treatment should be and often presents informed questions about what they have read. Where the information is not correct, I need to reeducate the patient. In either case, it typically leads to more time needed for an office visit than was needed in the past. That being said, where the information was good, it can lead to an overall positive interaction. Where the information was bad, in addition to the extra time needed, it can sometimes lead to unnecessary skepticism and even difficulty with the patient.

Research Question 2

Can self-help and health information websites influence consumer health behaviors and health outcomes? If yes, how?

The second research question in round 1 asked expert panelists if self-help and health information websites can influence consumer health behaviors and outcomes and how. In round 1, 25 of the 26 panelists believed that the use of the Internet for health information and self-help can influence consumer health behaviors and outcomes (96%), yet only 73% of round 3 panelists (16) agreed that it is the consumers' primary source of health- and symptom-related information. These findings are consistent with those of Buckley (2009), as many people choose to use Internet resources such as WebMD to play the role of a physician to self-diagnose and self-treat. With more than 54,700,000 results found in Google for the term health assessment tools and over 160 million Americans

access the Internet for health information (Google, 2007; Harris Poll, 2007), this has vast implications. Specifically, Panelist 10 stated,

The advent of Google and other search engines has made health, wellness, and medical searching available to millions of people. Health and medical searches are among the very top in terms of categories of searches, and this has been studied extensively. De facto, behaviors have changed.

In addition to consumer engagement, other common themes that emerged as a result of this question included consumer empowerment, patient/physician relationship and social support. General panelist consensus (92% in round 2) suggested that consumers are becoming more reliant on the Internet for health information. Consistent with Paidakula's (2006) findings showing that the use of the Internet influences consumer health behaviors, current findings show that consumers have become increasingly influenced by Internet-based health information and diagnostic tools in making health care decisions. Panelist 22 explained,

My primary experiences as a pediatrician are that (1) patients/parents are more likely than in the past to have tried a treatment that they have learned about on the Internet and (2) parents bring their children to the office possibly more frequently because of instances where they are concerned about a symptom that they have read about and are seeking reassurance that what their child has is not as serious as what they may have learned about. I am certain in medical fields outside of pediatrics one might expect health outcomes to be influenced to a greater extent. I could imagine people delaying proper diagnosis and treatment because of the ease with which the information is available to "self diagnose."

As the use of the Internet for health information becomes more widespread, risk to the overall consumer quality of care increases (Paidakula, 2006). Panelist 17 was predominantly concerned about the possibility and impact of consumer self-diagnoses, particularly if it was incorrect and hence delayed access to quality health care. Other panelists conveyed their belief that the utilization of web-based health information has increased the level of the patient/physician relationship and a patient's ability to make more informed health decisions. Panelist 18 explained,

It allows patients to think of their symptomatology and consider the most likely causes of their diseases. Thereby, they are able to make more informed decisions about their own health and feel empowered to do so. They can also ask health care providers for more detailed assistance by being well-acquainted with the subject matter of their complaints.

Consumers do not have the knowledge or training to make informed decisions about their health or successfully diagnose and treat themselves (Hardey, 1999; Lorence & Abraham, 2006). Panelist 11 referred to experiences in which patients using web-based health information had come to the consults with pre-determined diagnoses and requests for testing. Specifically, Panelist 11 mentioned:

Patients frequently present after having already determined what they believe the diagnosis to be and often requesting specific prescriptions or testing. I also see a lot of fear generated when patients read horror stories of rare and unusual illnesses. There was a famous email chain letter about ovarian cancer suggesting that every woman should demand the ca 125 test although it has not proven to be a good screening tool. Nonetheless I still see this email crop up now and again

even though the original writer has retracted it and the American College of GYN has responded to this too.

In further assessing the impact of the Internet on the patient/physician relationship, Panelist 7 suggested that doctor visits can be more productive as a result of information that patients bring with them and can help empower the patient towards greater involvement and collaboration with their health care provider. This is consistent with studies showing that rapid access to relevant health related information is highly beneficial as patients have limited time to discuss health care questions and concerns once they visit the office and finally see their physician (Tu & Cohen, 2008). Consensus could not be reached on whether such interactions resulted in better health outcomes. During Round 2, experts were asked if the Internet empowered patients and health care providers to partner in care and ensure better health outcomes. Responses to this two-part question generated marginal consensus (63%). The phrasing used in this question may have been vague. The question was rephrased in round 3 to eliminate ambiguity and focus on partnership rather than assurance of better health outcomes. Of the 22 physicians responding to round 3, 95% agreed that the Internet enabled patients and health care providers to partner for better health outcomes.

In addition to enhancing consumer engagement, empowerment, and the patient/physician relationship, the Internet can also serve as critical social support tools for patients and caregivers. The explosion of access to health-related information via the web can enhance serve as a source of support through the use of social media technology such as patient health blogs (Potts & Wyatt, 2002). Ninety-six percent of Round 2 panelists agreed that the Internet helps connect people with similar health problems, and

92% believed that it helps facilitate continuous dialogue between such people regardless of their geographic location.

While the panelists and prior studies confirm that the Internet enhances social support, research has shown that those who actively seek information may have poorer coping skills (O'Grady, Witterman, & Wathen, 2008). Weaver, Thompson, Weaver, and Hopkins (2009) found that consumers who spent more time on the Internet seeking health information were also non-adherent to medical advice and treatment recommendations, ascribed greater importance to health information available from mass media, demonstrated greater reliance on social media and social community support, experienced a poorer quality of life, and reported possessing higher self-efficacy. *Research Question 3*

In your experience, what have been some health risks associated with the use of self-help and health information websites by patients, consumers, and caregivers?

In assessing the health risks posed to consumers using self-help and health information websites, the common risk themes that emerged in response to research question 3 included those related to self-diagnosis, health consequences, and financial implications. The results revealed very high to moderately high consensus (86%) with the statement that consumers who use the Internet to self-diagnose have a limited view of the information and are at risk of misdiagnoses.

Among the health risks identified, 92% of experts responding to round 2 believed patients who use the Internet to access health information could stop taking necessary medications. This can be evidenced in the study by Weaver, Thompson, Weaver, and Hopkins (2009), which demonstrated that a considerate portion of consumers who were

actively using the Internet to seek out health information were going against the recommendations of their health care providers and engaging in alternative treatment strategies such as discontinuation or refusal of treatment. Eighty-six percent felt such use could delay access to physician care or increase the risk of inappropriate medication without the physician's knowledge. Panelist 3 elaborated,

Some of the inherent risks include delayed diagnosis, decreased compliance with medical therapy prescribed by physician because of conflicting information patient may encounter on the Internet, erroneous perception about the health care system, and influence decision making regarding use of "natural" products vs. FDA approved "drugs" that may or may not necessarily have the advertised beneficial effects.

While the panelists did identify certain health risks, they were not able to agree in round 2 that web-based health information empowers consumers to self-diagnose (58% agreement) and self-treat (54% agreement). This contradicts the research findings of Forkner-Dunn (2003), demonstrating that 41% of respondents claimed that the Internet did affect their health care decisions.

Panelist 5 suggested that informed consumers make partners that are more powerful for their physicians to collaborate with. This is in line with the social learning theory that states that the chance that a person will engage in particular behaviors is a result of that person's anticipation that such actions will generate specific outcomes as well as the perceived value of the resulting reinforcement (Wallston, 1997). There are negative health consequences associated with the social learning theory if consumers decide to substitute web-based information for self-diagnosis and self-treatment. This

subjective determination of one's abilities is also referred to as perception of control (Wallston, 1997). The more a person believes he or she is in control of a situation, the more likely he or she is to engage in a particular behavior. According to Zullkosky (2009), having too high of an estimate in one's beliefs could cause physical injury. Panelist 5 pointed out that legitimate websites specifically declare that the information does not qualify as medical advice and include a disclaimer that a health care professional be consulted. Panelist 9 provides additional insight,

Sometimes, the power of suggestion is quite strong. People will visit a site because they have a single symptom, and a friend that has suggested they may have a specific disease because they have this single symptom. The person visits the site and becomes convinced they have nearly all the other symptoms attributed to that specific disease. This prompts a visit to the physician, who then runs a battery of tests on the patient, only to find no suggestion of this illness. However, the patient is now convinced in their mind they have this disease, and seeks another opinion, and then another, and another... This actually occurs more often than one would imagine. I have seen these patients, and it takes the development of a strong patient-physician relationship to overcome. From this standpoint, unnecessary tests and procedures are performed, and these sometimes cause harmful side effects. Some tests, even as simple as a colonoscopy, can end with death. Patients also sometimes seek attention or specific care based on incorrect recommendations from the Internet. This can be quite expensive to the health care system, and take time away from patients who are actually sick.

Financial implications, such as elevated costs resulting from unnecessary care, have also been suggested as health risks associated with consumer use of health information websites. Panelist 17 suggested patients with no insurance or limited coverage may seek out resources on the Internet to find answers about their symptoms and condition to save money and minimize out-of-pocket expenses. The health risks associated with delayed access to care could include an exacerbated medical condition that is diagnosed and treated later rather than sooner, which may ultimately lead to added cost within the health care system. The overall safety, effectiveness, and efficacy Internet-based health assessment tools are difficult to predict (Levy & Strombeck, 2002), with implications that can be positive as well as negative. Levy and Strombeck (2002) suggested that the Internet, if used properly, can help reduce the cost of health care and has already transformed standard health care practices and health education, enabling the quick facilitation and exchange of large amounts of information to diverse audiences and communities across the globe. Potts and Whyatt (2002) suggests that, due to the lack of regulations and massive amounts of low-quality information, the use of the web can result in misunderstanding or misinterpretation of findings as well as higher costs of care associated with self misdiagnosis and mistreatment.

While 82% of round 3 panelists agreed that delays in proper medical care will result in higher costs to the health care system, there continues to be marginal consensus (64% in round 3) that the reason patients turn to the Internet for self-diagnosis is to minimize out-of-pocket health care expenses. Disagreements leading to this marginal consensus included responses such as "reasons are multiple and this is less important," "they do it for convenience/privacy," and "they want input, ideas, and referrals mostly."

Lack of consensus occurred when panelists were asked their views on the increase of physician and hospital visits resulting from consumer Internet use for self-diagnosis. While only 29% of respondents strongly agreed with that statement, 21% disagreed, and 50% were uncertain and neither agreed or disagreed. Similarly, panelists lacked consensus on whether or not hospital visits resulting from consumer self-diagnosis or misdiagnosis were expensive to the health care system. While 50% of panelists agreed that they were expensive, 17% did not agree, and 33% were uncertain. Lastly, panelists could not agree that consumer use of the Internet for self-diagnosis would increase the cost of health care in the long term. Forty-six percent were unsure, while 29% agreed, and 25% disagreed.

Research Question 4

In your experience, what have been the benefits of such tools?

The most common benefit themes uncovered in Question 4 of round 1 include empowerment, patient/physician relationship, and social support. Access to consumer support groups is of benefit to consumers, with 100% of responding physicians generating consensus to this statement. This is consistent with findings that show that the explosion of access to health-related information via the web can enhance a consumer's understanding of his or her condition, and can serve as a source of support through the use of social media technology such as patient health blogs (Potts & Wyatt, 2002). Weaver, Thompson, Weaver, and Hopkins (2009), however, demonstrated that consumers who were actively using the Internet to seek out health information also showed greater reliance on social media and web-based community support, were more

non-compliant to physician treatment recommendations, and reported to have higher selfefficacy.

Self-efficacy, a central part of social learning theory, represents a person's judgment of his or her own ability to perform activities resulting in specific outcomes. According to social learning theory, "awareness is influenced by the informative function of modeling and is more likely to adopt modeled behavior if it results in outcomes they value" (Bandura, 1977, p. 28). As such, self-efficacy can occur as a result of personal experience or from witnessing the successes of others and believing that they are capable of achieving the same outcomes and successes (Zullkosky, 2009).

Eighty three percent of panelists agreed that the Internet empowers patients to manage their own care. The subjective determination of one's abilities is also referred to as perception of control (Wallston, 1997). The more a person believes he or she is in control of a situation, the more likely he or she is to engage in that behavior. For example, Panelist 1 commented,

Greater "buy-in" with greater understanding, because there is a greater capacity to bring concerns to the table when the capacity to research is enabled. This requires the physician to be open to "stupid questions", and reframe any knowledge deficits in a manner that promotes deeper level of "buy in" such as compliance.

The patient/physician relationship can be enhanced as part of the benefits of using the Internet for health information. Eighty-six percent of round 3 panelists agreed that a growing number of patients are using the Internet to communicate with their health care providers. Panelist 16 explained that many of his patients often make the diagnosis before he does and are regularly bringing him new information. Panelists 7 suggested that there

is greater feeling of autonomy on the part of patients and less fear of doctors as authority figures who monopolize access to information.

Round 3 represented 86% consensus that using the Internet can positively impact the quality of health care, including joint benefits for consumers and the providers. With the recent shift to the Internet as a cost-effective and readily accessible tool for medical information and self-diagnosis, more patients are becoming actively involved in their own health care management (Levy & Strombeck, 2002). According to Panelist 8, patients can use the web-based health information to improve the quality of their own care and be better prepared for discussions with their doctors, while physicians can improve patient outcomes from their ability to easily access the latest medical research. While health information found on the Internet could stimulate physicians and patient collaboration, lack of consensus emerged when panelists were asked if the Internet had lead to more effective communication between patients and physicians. Only 45% agreed with the statement, while 36% were uncertain and neither agreed or disagreed. When asked if patients who used Internet information were easier for physicians to work with, 59% were uncertain and neither agreed or disagreed with this statement, while 32% agreed with this statement.

Research Question 5

Should the use of the Internet tools and websites be incorporated into health care practices? If yes, why? If yes, what types of strategies and policies can health leaders develop to ensure safe high-quality health care that incorporates the key resources and advantages available through the Internet?

Research question 5 generated an 88% consensus rate in round 1, with 23 of the responding 26 physicians agreeing that Internet tools and websites should be incorporated into health care practices. This is consistent with studies showing that rapid access to relevant health related information is highly beneficial as patients face challenges in making appointments to see their physicians and have limited time to discuss health care questions and concerns once they visit the office and finally see their physician (Tu & Cohen, 2008). Panelist 5 suggested that the reason for incorporating Internet tools into health care practices is that

Most appointments are too short to convey useable information, and that information is frequently forgotten. Instruction sheets can be lost. Reliable websites can be a physician's assistant. However, they can't be standalone websites. They need to be designed as extensions of the process of care.

A high level of consensus (92%) in round 2 reflects that it is not possible to restrict consumer access to health information available on the Internet, regardless of the source. Panelist 22 commented that since health care leaders cannot control who puts information on the Internet, it was up to physicians, medical societies, and public health officials and bodies to maintain accurate information and communicate to patients where to find it. Panelist 3 further suggested,

It is not possible to restrict patient access to all the information available on the Internet, regardless of the source. But one can at least direct them in the right direction by recommending specific sites with additional information, tools and resources regarding their medical condition(s). Also instant access to support

groups and online certified health care professionals (e.g. physicians, nurses, PAs, pharmacists, etc...) can be of additional benefit.

There was high consensus (96%) that health care professionals must play an active role in guiding patients to reliable web-based health information and that participatory medicine can be enriched using these sites. Panelist 24 provided insight:

There will need to be ways to ensure that Internet sites are reviewed and approved by physicians, specialty societies or another third party agency. I don't want to be overly bureaucratic, but without some way to review, approve and continuously update information to consumers, we run as much risk of disseminating wrong or incomplete information as we do disseminating good information. Control of an open architecture dynamic system such as the Internet can be difficult and will continue to be a challenge for the health care system.

As the Internet continues to emerge as a major transformational method for the provision of health information and care, questions remain about its effects on consumer health behaviors and outcomes (Weaver et al., 2009), and predicting and evaluating the overall safety, effectiveness, and efficacy of consumer Internet use for health information is difficult (Levy & Strombeck, 2002; Bundorf et al., 2006). According to Wallston (1997), health behaviors constitute health-related actions impacting one's health status, and include positive and negative health behaviors (Wallston, 1997). For health care leaders to ensure safe and high-quality health care that incorporates the key resources and advantages available through the Internet, 83% of round 2 panelists felt that it is important for medical societies and government agencies to join forces to develop, integrate, and make accessible their network of web-based information to consumers and

professionals alike. Panelist 14 suggested that this be incorporated into the health care provider's medical training, while panelist 8 encouraged policy leaders to develop a peer review process that tells the consumer that the information is safe and approved by a governing body that they trust. Policy changes that include incentives were also recommended (Panelist 23).

A high level of consensus (95%) was also reached by panelists in round 3, agreeing that in order to optimize consumer safety and reliability, health-related websites should be reviewed and certified as part of health care strategies and policy. There was lack of consensus from responding physicians in round 2 (n=24) on the need for governing bodies to specifically outline a list of websites that are deemed appropriate for consumer use. Forty-six percent stated that such bodies should define a specific list, while 29% disagreed, and 25% were uncertain and neither agreed nor disagreed. Panelist 20 suggested that for health care leaders to ensure safe high-quality health care that incorporates the key resources and advantages available through the Internet, the United States needs greater involvement and funds from the federal government. Specifically, Panelist 20 commented,

There should be some sort of high level impetus for this. Starting with the federal government, there should be groups of people in charge of figuring out how to use the Internet. There should be a hierarchical or tree like chain of command or association down the local level to make sure that there is uniformity across the country. There should also be a way for the top to listen to the bottom and attend to the flow of information that comes from the front lines. I think that federal money needs to be used, and that starting from the top, interdisciplinary teams

should be organized that include knowledgeable policy people, politicians, health care providers and IT specialists.

While there was high agreement that health care professionals must incorporate the Internet into their practices, panelists showed minimal consensus (less than 60%) on whether physicians are currently increasing their use of the Internet to stay connected with patients (54% agreement). While a high degree of consensus (91% in round 2) revealed that health professionals can optimize patient care with the use of the Internet and that the Internet can positively impact the quality of health care (86% in round 3), 86% also agreed that responding to patient emails and web requests took time away from reimbursed patient care. Specifically, panelist 20 pointed out that an average single practitioner or small group practice may not be able to do this without reimbursement, and that while there could be a benefit the current reimbursement system makes this nothing more than an uncompensated burden.

Findings revealed that reimbursed web-based patient/physician interactions are not the norm, but are frequently suggested as a positive use of Internet capacity. Given the reality of minimal web-based reimbursed medical services, nominal consensus among panelists may have revealed a lack of clarity and certainty about whether or not direct and reimbursed care provided by a physician via the Internet would be beneficial to the patient (58% agreed, 33% were uncertain, and 9% disagreed) and whether such interactions would ultimately help improve the effectiveness of communication (42% agreement) between patients and health care providers. Expert 24 suggested,

If there are truly valuable tools that can reinforce the care messages intended by the physician, then they can be an ongoing resource for patients. If these tools can be personalized for both the patient and the physician practice (within acceptable standards and guidelines) then they may have more impact on patients. I am not sure, however, that health information delivered on the Internet has any more impact than similar information in print and other electronic forms (e.g. audio or video). It is my impression that generally none of these modalities has a high success rate unless the patient has motivation to engage and change. The key to success is basically how can we engage more patients to change or be motivated to change their health behaviors.

Appendix G provides a list of all recommended strategies and policies provided by panelists that can be used to develop and ensure safe high-quality health care incorporating the key resources and advantages available through the Internet.

Research Question 6

How could health professionals including doctors, nurses, pharmacists and even health librarians be integrated into the web-based health information model to support consumers in need?

Common themes that have emerged in response to question 6 include health oversight, and financial implications. Eighty-three percent of panelists agree that it is critical for health professionals to develop informed health consumers who know where to look for credible health information, while 23 of the 24 panelists to Round 2 (96%) suggest that health care leaders need to study how to best incorporate Internet tools into the overall care continuum. Panelist 17 suggests that we need a web framework that offers health-related information to consumers yet facilitates the connection with health care professionals to get involved in health decision at times of importance, and 91% of

Round 3 panelists agree that on-line access to certified health care professionals would be of benefit to consumers. Panelist 3 comments,

Real time assistance with medication questions (e.g. dose, side effects, etc...) provided by a pharmacist and triage of symptoms by a certified nurse, and even direct patient care provided by a physician via the Internet would be of extreme value for certain specialties, especially those that rely highly on laboratory tests and patient history for diagnosis and treatment such as Endocrinology.

Panelist 2 believes that health librarians will have a very bright future in an integrated web-based health information model that supports consumers in need of health information. Panelist 2 also suggests that younger doctors growing up in the time of the Internet will have an easier time 'incorporating' the web into their practices than older physicians. According to panelist 10, practices around the country have already started to integrate web-based health care delivery models into their practices in an effort to solve problems, reduce costs, and support patients in need. Panelist 10 suggests,

Physicians and nurses around the country are engaging with their patients online in e-visits of various kinds, and solving problems and answering questions without the need for expensive travel, for example. I expect to see advances in the uses of personal health record system to guide both physicians and patients toward care that works, and to steer them away from treatments that don't work.

While there is agreement that health professionals including doctors, nurses, pharmacists, and even health librarians could and should be integrated into the web-based health information model and overall care continuum to support consumers in need of medical advice or attention, a lack of consensus demonstrated uncertainty whether or not

such real-time assistance would ultimately deliver safer patient care. Fifty-eight percent of panelists agreed that such assistance would enable safer care, 29% were uncertain and neither agreed or disagreed, and 13% disagreed with that statement.

While the consensus of ensuring safer care could not be reached, a high level of consensus (79%) was reached that the majority of Internet-based health information accessible by consumers has not been reviewed and validated by legitimate health care professionals or organizations. Panelists 4 and 22 discussed the need for health care providers to direct their patients to sites that are accurate and relevant to their particular needs. The variety of accurate and relevant sites includes not only information sites, but also support groups, access to information about clinical trials, etc. Providers also will need to become increasingly comfortable with the use of telemedicine.

Eighty-three percent of round 2 responses confirmed that only a few innovative health plans reimburse for e-mails exchanges and Internet-based interactions with patients. Panelist 8 commented on the importance of outcomes-based payments, suggesting that health care providers who incorporate such tools into their health care models should have a way to bill for the experiences that patient receives, as a way to be compensated for their efforts. Models such as RelayHealth that provide a compensated medium for interaction without the need for formal visits were also recommended (Panelist 17).

Appendix H provides a list of all expert recommendations of how health professionals such as doctors, nurses, pharmacists and even health librarians could be integrated into the web-based health information model to support consumers in need.

Conclusion

A review of literature and expert panelists' consensus in the study recognized the changing trends toward consumer utilization of the Internet for health related information along with potential issues and opportunities, and challenged panelists to define recommendations in maximizing the use of web-based health assessment tools to expose benefits while minimizing the risks. A full list of expert recommendations on strategies and policies that health leaders can develop to ensure safe high-quality care is presented in Appendix G. Recommendations of how health professionals including doctors, nurses, pharmacists, and health librarians could be integrated into the web-based health information model to support consumers in need is documented in Appendix H.

An important purpose of the current study was to help health care and other leaders break new ground, go beyond the known, and help create the future of online consumer self-help tools based on recommendations that may be identified as a result of the findings from the study (Darling & Beebe, 2007). The predictions on how such tools could positively and negatively affect the stakeholders could enable future studies in the design of action plans and changes that need to be made to maximize the strengths of the Internet while minimizing the weaknesses.

With the explosion of Internet as a major transformational tool for the provision of health information and care, little is known about its effects on consumer health behaviors and health outcomes (Weaver et al., 2009). As health care leaders seek to develop health care plans that incorporate the use of Internet-based self-assessment tools into quality health management shared between the doctor and patient, the criticality of

understanding consumer health benefits and risks is critical and can be used as the groundwork in future studies.

The current study led to the discovery of flaws and strengths in the current system, which could ultimately lead to the transformation and optimal use of Internet-based health information and tools by consumers and health care providers. The insights provided by the expert study participants help confirm that Internet sources have been influential in helping consumers obtain health information (Forkner-Dunn, 2003). Study findings support the literature review and validate the importance of this study.

The strong consensus from the expert panelists that the Internet has changed health care by placing vast amounts of health information and resources literally at the fingertips of physicians, patients, care managers, health providers, and other individuals engaged in health care has massive implications in generating positive health awareness. With the recent shift to the Internet as a cost-effective and readily accessible tool for medical information and self-diagnosis, more patients are becoming actively involved in their own health care management (Levy & Strombeck, 2002). The growing use of medical websites to obtain health care offers varying benefits to consumers that include convenience and access (Martin, 2000). Distribution of medical information to millions of people in the United States (Rajendran, 2001) has been providing a significant opportunity for patients to become directly involved in their own health care (Forkner-Dunn, 2003). Rapid access to relevant health related information is highly beneficial as patients face challenges in making appointments to see their physicians and have limited time to discuss health care questions and concerns once they visit the office and finally see their physician (Tu & Cohen, 2008).

The explosion of access to health-related information via the web can also enhance a consumer's understanding of his or her condition, and can serve as a source of support through the use of social media technology such as patient health blogs (Potts & Wyatt, 2002). According to the panelist consensus, the use of the Internet has enabled like-minded patients to connect with each other for social support as well as feel more empowered to communicate with their health care providers about a condition. While the growing availability and use of Internet health tools can benefit the global expansion of consumer awareness and participatory medicine, these tools may also expand the chance of consumer health risks associated with information inaccuracy and the breakdown in the patient/physician relationship because of the growing number of consumers not seeking help or advice of a physician after self-diagnosis (Kerka, 2003).

As the use of the Internet for health information becomes more widespread, risk to the overall consumer quality of care increases (Paidakula, 2006). General panelist consensus (92%) suggested that because advice found on the Internet from random websites or as patient support blogs can be wrong or misleading, the impact of consumer access to such false information is more negative than positive. Identifying fraudulent sites is not easy for many consumers (Tedeschi, 2005). Because of the lack of regulations and massive amounts of low-quality information, the use of the web can result in misunderstanding or misinterpretation of findings as well as self misdiagnosis and mistreatment (Potts & Wyatt, 2002). As such, expert panelists agree that consumers making health decisions based solely on information they have obtained on the Internet can be put at risk by self-diagnosing, self-treating, or delaying care. Recommendations for future safe and effective use included a review and certification process for health-

related websites, as well as on-line and reimbursed access to certified health care professionals such as physicians, nurses, pharmacists, and health librarians.

Predicting and evaluating the overall safety, effectiveness, and efficacy of consumer Internet use for health information is difficult, and further research is needed to explore how this information influences the health care decision-making of consumers and how it affects their health outcomes. Based on the challenges and opportunities presented in this study, expert panelists agree that health care professionals must play an active role in web-based health and in guiding patients to reliable web-based health information. High consensus showed that on-line access to certified health care professionals would be of benefit to consumers, and that it is critical for health professionals to develop informed health consumers who know where to look for credible health information. The majority also agreed that such engagement strategies are currently not reimbursed by a majority of health plans, and would take time away from reimbursed patient care.

While these interactions could be of benefit to both consumers and health care providers, the panelists also suggested that the current reimbursement system makes this nothing more than an uncompensated burden. Changes to health insurance compensation structures that include web-based interaction are recommended. Additionally, recommendations for future safe and effective use included a review and certification process for health-related websites, as well as on-line and reimbursed access to certified health care professionals such as physicians, nurses, pharmacists and health librarians.

Concluding Remarks

The scope of the current study was to seek insight and gain opinion from experts in the field treating patients on the risks and benefits that such tools deliver as part of health care as well as gain insight into recommendations for future changes necessary in minimizing the risk and empowering better patient awareness and physician integration. While the benefits of the Internet are clear for both consumers and health care providers through its immediate access to health information, medical leaders cannot ensure a safe, cost-effective, and quality health care environment as a growing number of consumers continue using the Internet for health information (Herrick, 2005; Tyson, 2000).

While the growing availability and use of Internet health tools can benefit the consumer awareness and participatory medicine, these tools may also expand the chance of consumer health risks (Kerka, 2003). As the use of the Internet for health information becomes more widespread, so does the risk to the overall quality of care (Paidakula, 2006). Consensus suggests that advice found on the Internet from random websites or patient support blogs can be wrong or misleading. Consumers making health decisions based solely on this information can be put at a health risk as a result of self-diagnosing, self-treating, or delaying care. Health care professionals must play an active role in webbased health and in guiding patients to reliable web-based health information.

Reimbursement for such care must be provided, and stronger oversight and regulatory controls over content need to be put in place, including peer-reviewed medicine-based certification from recognizable government bodies or medical associations.

Recommendations and Suggestions for Future Studies

The current Delphi study provides recommendations for the development of plans to incorporate the use of Internet-based self-assessment tools into standard care practices; minimizing potential health risks while providing recommendations for safe and cost-effective uses of such tools. As the use of the Internet for health information becomes more widespread, so does the risk of decreasing consumer quality of care (Paidakula, 2006). Patient safety is an important issue for lobbyists, special interest groups, and political action groups such as the American Medical Association's (AMA) (2007). While these and other groups have supported legislative efforts and even formed political action groups to improve the health care environment for patients, expert responses demonstrate a critical consensus (95%) for review that is more stringent and certification policies optimizing the accuracy of web-based health information and ultimately consumer safety and reliability. Such policies may include political and financial commitment to improving the quality of web-based health information as well as the removal of possible political, business and regulatory barriers.

There is strong panel consensus that the health risks associated with delayed access to care could include exacerbated medical conditions that are diagnosed and treated later rather than sooner, and would ultimately lead to added costs within the health care system. Panelists did not agree that there was an increase of physician and hospital visits resulting from consumer Internet use for self-diagnosis. Further research is needed to explore how this information influences the health care decision-making of consumers and how it affects their health outcomes (Bundorf et al., 2006). Additional research is recommended to study the correlation between consumer use of the Internet

for health information and their health actions and outcomes, which can include but are not limited to increased hospital and physician visits, self-diagnosis, self-treatment, self-medication, and delayed medical care.

Panelist recommendations on strategies and policies that health leaders can develop to ensure safe high-quality as well as how health professionals including doctors, nurses, pharmacists, and even health librarians could be integrated into the web-based health information should also be carefully reviewed and implemented by health care leaders in collaboration with government, provider, consumer, and insurer stakeholders. While little is known about the effects of Internet-based health tools and information on consumer health outcomes (Weaver et al., 2009), health behaviors do constitute health-related actions impacting one's health status and include activities such as seeking health information, physician visits as well as smoking and even drug use (Wallston, 1997). Such behaviors, either positive or negative, represent the theoretical underpinnings of social learning theory (Cassell, Jackson, & Cheuvront, 1998) with implications that need to be further studied.

Social learning theory states that the chance that a person will engage in particular behaviors is a result of that person's anticipation of positive outcomes and a perceived value of the results (Wallston, 1997). These behaviors are reconciled by a perceived threat of a specific health outcome, by the barriers or benefits to taking a particular action, or by an expected reduction to threat as a result of taking action (Cassell et al., 1998). Based on the potential risks and subsequent cost to care of such actions, a recommendation for health care leaders to conduct long-term quantitative analyses examining the impact of health-related Internet tools on consumer health behaviors,

health outcomes, and cost consequences is recommended. Particular importance should be placed on studies examining the health behaviors and outcomes of young invincibles, uninsured, and cyberchondriacs (Buckley, 2009; Lorence & Abraham, 2006; Shrieves, 2009) as well as minority groups and communities (Tu & Cohen, 2008).

A qualitative consumer perspective on the impact of web-based health assessment tools on their health behaviors and outcomes is also recommended, which should include an assessment of the usefulness of real-time physician access on consumer health behaviors, outcomes and cost of care as well as capture their perceived value of web-site peer-review and certification. Finally, future research should be done to assess how peer-reviewed, certified health sites that provide consumers with real-time access to health care professionals impact consumer health behaviors, outcomes and costs of care. By meeting the needs of consumers, providers, and health care leaders, everyone benefits.

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APPENDIX A: INVITATION TO PARTICIPATE IN STUDY

| Dear Dr. | | |
|----------|--|--|
| Deal Di. | | |

I would like to invite you to take part in a research study entitled *Ramifications of Web-Based Health Assessment Tools on Consumer Behaviors and Health Outcomes*, as part of the final requirements in completion of my Doctorate in Health Administration.

With the distribution of medical information to nearly 100 million people in the United States, the Internet has been rapidly changing the consumer's view of medicine by providing a key opportunity for consumers and patients to become actively involved in the provision of their own health care. While the growing availability and use of Internet health tools can benefit the global expansion of consumer awareness and ease access, the tools may also expand the chance of consumer health risks associated with a breakdown in the patient/physician relationship because of the growing number of consumers not seeking help or advice of a physician after self-diagnosis.

The purpose of this study is to:

- Explore expert opinion about ramifications of web-based health assessment tools including
 potential health benefits and risks that such tools can have on patient health behaviors and
 health outcomes.
- Explore recommendations for best practices in incorporating web-based health assessment tools into quality health care and continuing health management.

This Delphi study will be made up of three waves of questionnaires, which will be disseminated to the final panel over a two-month time period. During each wave, each panelist will receive a questionnaire for response. The first survey will contain 6 open-ended questions, where you can write as much or as little as you want. Each survey will take approximately 20-30 minutes (depending on your level of involvement and the depth of your answers), and your time investment in this project is appreciated. Data will compiled in a secure environment, and only the researchers see raw data. Your personal information will not be recorded and, therefore, will not be connected to any of your responses. All of your answers will be anonymous. Completing this survey is completely voluntary, and you may quit at any time.

Please note that only practicing physicians who meet the following criteria will be able to participate in this study.

- 1. Five or more years working experience as a practicing physician
- 2. Seeing more than 10 patients per day
- 3. Have experience with patients who use of the Internet for health-related information

Your participation in this research study is extremely valuable. Your responses can help maximize the use of the Internet for health-related issues, while minimizing the risks and improving overall health. If you meet the aforementioned criteria and are interested in participating in this survey, please respond to me by email at sdorfman@optonline.net.

Thank you in advance for your consideration of participating in this research. If you have any questions, the researcher can be reached at sdorfman@optonline.net or by phone at 732.208.9057.

Susan Dorfman

Doctoral Candidate Health Administration University of Phoenix

APPENDIX B: INFORMED CONSENT STATEMENT

My name is Susan Dorfman, and I am a student at the University of Phoenix working on a Doctor of Health Administration degree. I am conducting a research study entitled Ramifications of Web-Based Health Assessment Tools on Consumer Behaviors and Health Outcomes. The purpose of the research study is to explore expert opinion about ramifications of web-based health assessment tools including potential health benefits and risks that such tools can have on patient health behaviors and health outcomes, and gain recommendations for best practices in incorporating web-based health assessment tools into quality health care and continuing health management.

Your participation will involve responding to three surveys over a one-month time period, each taking no more than 30 minutes of your time. Your participation in this study is voluntary. If you choose not to participate or to withdraw from the study at any time, you may do so without penalty or loss of benefit to yourself. The results of the research study may be published, but your identity will remain confidential and your name will not be disclosed to any outside party.

In this research, there are no foreseeable risks to you.

Although there may be no direct benefit to you, a possible benefit of your participation is the development of recommended plan that incorporates the use of Internet-based selfassessment tools by adult consumers into quality health management.

If you have any questions concerning the research study (either during or following the study), please contact me at 732.208.9057 or sdorfman@optonline.net.

As a participant in this study, you should understand the following:

- 1. You may decline to participate or withdraw from participation at any time without consequences.
- 2. Your identity will be kept confidential.
- 3. [], the researcher, has thoroughly explained the parameters of the research study and all of your questions and concerns have been addressed.
- 4. Data will be stored in a secure and locked area. The data will be held for a period of three years, and then destroyed.
- 5. The research results will be used for publication.

"By signing this form you acknowledge that you understand the nature of the study, the potential risks to you as a participant, and the means by which your identity will be kept confidential. Your signature on this form also indicates that you are 18 years old or older and that you give your permission to voluntarily serve as a participant in the study described."

| eSignature of the interviewee | Date |
|-------------------------------|------|
| _ | |
| eSignature of the researcher | Date |

APPENDIX C: INITIAL PARTICIPANT QUESTIONNAIRE

| 1. | How has the Internet changed health care? |
|----|------------------------------------------------------------------------------------|
| 2. | Can self-help and health information websites influence consumer health |
| | behaviors and health outcomes? |
| | YesNo |
| | a. If yes, how? |
| 3. | In your experience, what have been some health risks associated with the use of |
| | self-help and health information websites by patients, consumers and caregivers? |
| 4. | In your experience, what have been the benefits of such tools? |
| 5. | Should the use of the Internet tools and websites be incorporated into health care |
| | practices? |
| | YesNo |
| | a. If Yes, why? |
| | b. If Yes, what types of strategies and policies can health leaders develop |
| | to ensure safe high-quality health care that incorporates the key |
| | resources and advantages available through the Internet? |
| 6. | How could health professionals including doctors, nurses, pharmacists and even |
| | health librarians be integrated into the web-based health information model to |
| | support consumers in need? |

APPENDIX D. ROUND 2 PARTICIPANT QUESTIONNAIRE

Instructions: Please Insert an X on the Left of the Answer That Best Represents Your Response

| Inform | nation Access | | | | | | | |
|--------------|-------------------------------------|-----------------|----------|----------------|----------|------------------|--------|----------------------|
| 1. | The Internet give | s consumers fa | ister ac | cess to hea | lth info | rmation | | |
| | Strongly Agree | Agree | | Neutral | | Disagree | | Strongly Disagree |
| 2. | The Internet give | s physicians ra | pid acc | cess to clinic | al info | rmation | | y |
| | Strongly Agree | Agree | | Neutral | | Disagree | | Strongly Disagree |
| 3. | The Internet is a | disorganized re | eposito | ry of informa | ition | | | |
| | Strongly Agree | Agree | | Neutral | | Disagree | | Strongly Disagree |
| 4. | Consumers are b | pecoming more | reliant | on the Inter | net | | | |
| | Strongly Agree | Agree | | Neutral | | Disagree | | Strongly Disagree |
| 5. | Health profession information webs | | an activ | e role in gui | ding p | atients to relia | able I | nealth |
| | Strongly Agree | Agree | | Neutral | | Disagree | | Strongly Disagree |
| Inform 1. | nation Accuracy The greatest cha | | | ited informat | ion fou | und on the Int | erne | t is |
| | Strongly Agree | Agree | | Neutral | | Disagree | | Strongly Disagree |
| 2. | The majority of Ir reviewed and val | | | | | | | has not been |
| | Strongly Agree | Agree | | Neutral | | Disagree | | Strongly Disagree |
| 3. | The majority of Ir misleading | nternet-based h | ealth ir | nformation a | ccessi | ble by consur | ners | is false and |
| | Strongly Agree | Agree | | Neutral | | Disagree | | Strongly Disagree |
| 4. | Access to unfilter | red information | can ha | ve a negativ | e imp | act on consur | ner h | ealth |
| | Strongly Agree | Agree | | Neutral | | Disagree | | Strongly Disagree |

| 5. | The Internet poses a consumer risk of misdiagnosing due to a "limited view" of information provided | | | | | | |
|-------------|---------------------------------------------------------------------------------------------------------------------------|--------------------|---------------------|----------------------|----------------------|--|--|
| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree | | |
| Social S | upport | | | | | | |
| 1. | The Internet help | os facilitate conr | nections between pa | atients with commor | n health problems | | |
| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree | | |
| 2. | Advice found on | patient support | blogs can be wrong | g or misleading | | | |
| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree | | |
| 3. | The Internet ma regardless of time | | | ers to communicate | with each other | | |
| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree | | |
| Empow 1. | rerment Web-based hea | Ith information e | mpowers patients to | o manage their own | health | | |
| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree | | |
| 2. | Web-based hea | Ith information e | mpowers consumer | rs to self-diagnose | | | |
| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree | | |
| 3. | Web-based hea | Ith information e | mpowers consumer | rs to self-treat | | | |
| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree | | |
| Patien | t/Physician Rela | • | tient care provided | by health care profe | essionals | | |
| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree | | |
| 2. | The Internet has | increased com | munication betweer | patients and provid | ders | | |
| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree | | |

| | More and more providers | patients are turn | ng to the internet to | Communicate with | their fleath care |
|-------|----------------------------------------------------------------|----------------------------------------------|----------------------------------------|--------------------------------------------------|--------------------------------------------------------------------|
| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree |
| 4. | Physicians are patients | increasingly using | g web-based comm | unication tools to st | ay connected with |
| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree |
| 5. | The Internet ha | s improved comm | nunication between | patients and provid | ers |
| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree |
| 6. | | the Internet as the nedical condition | eir primary source o | of information after | being diagnosed |
| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree |
| 7. | | ay proper diagnos vailable to "self di | sis and treatment be agnose | ecause of the ease | with which the |
| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree |
| elf-D | iagnosis | | | | |
| 1. | Patients turn to | the Internet to se | lf-diagnose perceive | ed ailments | |
| | Strongly Agree | Agree | Neutral | Disagree | Strongly |
| | | | | | Disagree |
| 2. | The use of web treatment | n-based health ass | sessment tools by c | | Disagree |
| 2. | | o-based health ass | sessment tools by c | | Disagree |
| 2. | treatment Strongly Agree Patients turn to | Agree | Neutral eir primary source of | onsumers can dela | Disagree y necessary Strongly Disagree |
| | treatment Strongly Agree Patients turn to | Agree the Internet as th | Neutral eir primary source of | onsumers can dela | Disagree y necessary Strongly Disagree |
| | Strongly Agree Patients turn to symptoms they Strongly Agree | Agree the Internet as the want to find out n | Neutral eir primary source onore about | onsumers can dela Disagree of information when | Strongly Disagree Strongly Disagree they have Strongly Disagree |

| | a physician's kr | nowledge | | | |
|-----------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------|
| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree |
| 6. | Patients seek u the Internet. | nnecessary phys | sician care as a resu | ult of incorrect reco | mmendations fron |
| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree |
| 7. | Information obtained the lateral through through the lateral through through the lateral through the lateral through the lateral through the lateral through through the lateral through through the lateral through through through the lateral through through the lateral through through the lateral through through the lateral through through through the lateral through through the lateral through through the lateral through through the lateral through through through through through t | | rnet can cause pation | ents to delay seekir | ng care from a |
| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree |
| and 1. | cial Implications Delays by cons | | ing proper care resu | ılt in added costs to | the system |
| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree |
| 2. | Physician and harmonic Internet to self- | • | e increased as a re | sult of consumers | who use the |
| | | | | | |
| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree |
| 3. | Agree Physician and h | | ulting from consume | | Disagree |
| 3. | Agree Physician and h | nospital visits res | ulting from consume | | Disagree |
| 3. | Physician and hexpensive to the Strongly Agree In an attempt to | nospital visits res e health care sys | ulting from consume stem Neutral Neutral | er self-diagnosis or Disagree | misdiagnosis are Strongly Disagree |
| | Physician and hexpensive to the Strongly Agree In an attempt to | nospital visits rese health care sys | ulting from consume stem Neutral Neutral | er self-diagnosis or Disagree | misdiagnosis are Strongly Disagree |
| | Physician and hexpensive to the Strongly Agree In an attempt to answers about Strongly Agree A growing cons | Agree Agree Agree Agree Agree | Neutral Neutral Neutral Neutral Neutral Neutral | Disagree Disagree Disagree Disagree | Disagree misdiagnosis are Strongly Disagree ernet to find Strongly Disagree |
| 4. | Physician and hexpensive to the Strongly Agree In an attempt to answers about Strongly Agree A growing cons | Agree Agree Agree Agree Agree Agree Agree Agree | Neutral Neutral Neutral Neutral Neutral Neutral | Disagree Disagree Disagree Disagree | Disagree misdiagnosis are Strongly Disagree ernet to find Strongly Disagree |
| 4. | Physician and rexpensive to the Strongly Agree In an attempt to answers about Strongly Agree A growing consincrease the co Strongly Agree | Agree Agree | ulting from consume stem Neutral atients seek out to read conditions Neutral neutral | Disagree Disagree Disagree Disagree Disagree Disagree Disagree Disagree | Disagree misdiagnosis are Strongly Disagree ernet to find Strongly Disagree I diagnosis will Strongly Disagree |

| 7. | Only a few innover patient | rative neatti pia | | | |
|------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------|-----------------------------------------------------------------------------------|----------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------|
| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree |
| alth 1. | Consequences The Internet ena | • | nd health care prov | iders to partner in ca | are and ensure |
| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree |
| 2. | Health-related in | formation availa | able today can have | e a negative impact | on patient health |
| | Strongly Agree | Agree | Neutral | Disagree | Strongly Disagree |
| 3. | | | websites can have th care professiona | a positive impact or ls | n the overall |
| | | • | • | | |
| alth 1. | _ | | • | Disagree | Strongly Disagree |
| | Oversight Governing bodie information for the | es need to outlin | | ites that are deeme | Disagree d appropriate Strongly |
| | Agree Oversight Governing bodie information for the Strongly Agree | es need to outling the public at han Agree | ne a specific list of s d to review on the l | ites that are deemed | Disagree d appropriate Strongly Disagree |
| 1. | Oversight Governing bodie information for the Strongly Agree Health websites | es need to outling the public at han Agree | ne a specific list of s d to review on the l | ites that are deemed nternet Disagree | Disagree d appropriate Strongly Disagree |
| 1. | Agree Oversight Governing bodie information for the Strongly Agree Health websites care Strongly Agree Real-time, web-leading web-lead | es need to outling public at han Agree with real-time at Agree | ne a specific list of s d to review on the l Neutral assistance from hea | Disagree Disagree Disagree Disagree Disagree Disagree Disagree | Disagree d appropriate Strongly Disagree Is will ensure saf Strongly Disagree |
| 1. 2. | Agree Oversight Governing bodie information for the Strongly Agree Health websites care Strongly Agree Real-time, web-leading web-lead | es need to outling public at han Agree with real-time at Agree | ne a specific list of sid to review on the line line line line line line line lin | Disagree Disagree Disagree Disagree Disagree Disagree Disagree | Disagree d appropriate Strongly Disagree Is will ensure saf Strongly Disagree |
| 1. | Oversight Governing bodie information for the Strongly Agree Health websites care Strongly Agree Real-time, web-lin cost-reduction Strongly Agree | Agree Agree | Neutral Neutral Neutral Neutral Neutral Neutral Neutral Neutral | Disagree Disagree Disagree Disagree Disagree Disagree Disagree | Disagree d appropriate Strongly Disagree Is will ensure safe Strongly Disagree ssionals will resurce Strongly Disagree ssionals will resurce |

| 5. | Direct and reimbursed patient care provided by a physician via the Internet is beneficial to |
|----|----------------------------------------------------------------------------------------------|
| | the provider |

| S | Strongly | Agree | Neutral | Disagree | Strongly |
|---|----------|-------|---------|----------|----------|
| A | Agree | | | | Disagree |

6. Direct and reimbursed patient care provided by a physician via the Internet is beneficial to the insurer

| Strongly | Agree | Neutral | Disagree | Strongly |
|----------|-------|---------|----------|----------|
| Agree | | | - | Disagree |

APPENDIX E: TABULATED LIKERT-TYPE SCALE RESULTS FOR ROUND 2

| | | | | | | Consensus | Consensus | | |
|-----------------|----|----|----|----|----|-----------|-----------|-----|------|
| Statement | 1 | 2 | 3 | 4 | 5 | Total | % | Mdn | Mean |
| 1 | 1 | 1 | 0 | 6 | 16 | 22 | 91.67% | 5 | 4.46 |
| 2 | 0 | 0 | 1 | 10 | 13 | 23 | 95.83% | 5 | 4.5 |
| 3 | 0 | 0 | 4 | 5 | 15 | 20 | 83.33% | 5 | 4.46 |
| 4 | 0 | 0 | 1 | 9 | 14 | 23 | 95.83% | 5 | 4.54 |
| 5 | 0 | 2 | 5 | 10 | 7 | 17 | 70.83% | 4 | 3.92 |
| 6 | 0 | 0 | 8 | 8 | 8 | 16 | 66.67% | 4 | 4 |
| 7 | 0 | 0 | 0 | 7 | 17 | 24 | 100.00% | 5 | 4.71 |
| 8 | 0 | 1 | 0 | 6 | 17 | 23 | 95.83% | 5 | 4.62 |
| 9 | 1 | 4 | 5 | 7 | 7 | 14 | 58.33% | 4 | 3.62 |
| 10 | 0 | 0 | 2 | 8 | 14 | 22 | 91.67% | 5 | 4.5 |
| 11 | 0 | 1 | 0 | 9 | 14 | 23 | 95.83% | 5 | 4.5 |
| 12 ^a | 13 | 8 | 1 | 2 | 0 | 21 | 87.50% | 1 | 1.67 |
| 13 | 0 | 3 | 2 | 13 | 6 | 19 | 79.17% | 4 | 3.92 |
| 14 | 0 | 11 | 8 | 4 | 1 | 5 | 20.83% | 3 | 2.79 |
| 15 | 0 | 1 | 2 | 6 | 15 | 21 | 87.50% | 5 | 4.46 |
| 16 | 0 | 0 | 1 | 18 | 5 | 23 | 95.83% | 4 | 4.17 |
| 17 | 0 | 0 | 2 | 13 | 9 | 22 | 91.67% | 4 | 4.83 |
| 18 | 0 | 0 | 2 | 14 | 8 | 22 | 91.67% | 4 | 4.25 |
| 19 | 0 | 2 | 2 | 17 | 3 | 20 | 83.33% | 4 | 3.87 |
| 20 | 2 | 5 | 3 | 11 | 3 | 14 | 58.33% | 4 | 3.33 |
| 21 | 4 | 2 | 5 | 10 | 3 | 13 | 54.17% | 4 | 3.25 |
| 22 | 0 | 4 | 13 | 5 | 2 | 7 | 29.17% | 3 | 3.21 |
| 23 | 1 | 2 | 5 | 13 | 3 | 16 | 66.67% | 4 | 3.62 |
| 24 | 1 | 6 | 5 | 10 | 2 | 12 | 50.00% | 4 | 3.25 |
| 25 | 1 | 3 | 4 | 13 | 3 | 16 | 66.67% | 4 | 3.58 |

| 26 | 1 | 5 | 5 | 11 | 2 | 13 | 54.17% | 4 | 3.33 |
|-----------------|---|----|----|----|----|----|--------|-----|------|
| 27 | 1 | 5 | 8 | 7 | 3 | 10 | 41.67% | 3 | 3.25 |
| 28 | 1 | 4 | 4 | 12 | 3 | 15 | 62.50% | 4 | 3.5 |
| 29 | 0 | 1 | 1 | 18 | 4 | 22 | 91.67% | 4 | 4.04 |
| 30 | 0 | 1 | 2 | 10 | 11 | 21 | 87.50% | 4 | 4.29 |
| 31 | 0 | 1 | 2 | 13 | 8 | 21 | 87.50% | 4 | 4.17 |
| 32 | 1 | 1 | 5 | 6 | 11 | 17 | 70.83% | 4 | 4.04 |
| 33 | 0 | 5 | 12 | 7 | 0 | 7 | 29.17% | 3 | 3.08 |
| 34 | 1 | 3 | 8 | 11 | 1 | 12 | 50.00% | 3.5 | 3.33 |
| 35 | 0 | 0 | 9 | 12 | 3 | 15 | 62.50% | 4 | 3.75 |
| 36 | 1 | 5 | 11 | 7 | 0 | 7 | 29.17% | 3 | 3 |
| 37 | 0 | 2 | 6 | 8 | 8 | 16 | 66.67% | 4 | 3.92 |
| 38 | 0 | 0 | 4 | 12 | 8 | 20 | 83.33% | 4 | 4.17 |
| 39 | 0 | 1 | 8 | 13 | 2 | 15 | 62.50% | 4 | 3.67 |
| 40 ^a | 7 | 14 | 3 | 0 | 0 | 21 | 87.50% | 2 | 1.83 |
| 41 | 0 | 2 | 5 | 14 | 3 | 17 | 70.83% | 4 | 3.75 |
| 42 | 0 | 3 | 12 | 8 | 1 | 9 | 37.50% | 3 | 3.29 |
| 43 | 1 | 6 | 6 | 6 | 5 | 11 | 45.83% | 3 | 3.33 |
| 44 | 0 | 3 | 7 | 11 | 3 | 14 | 58.33% | 4 | 3.58 |
| 45 | 0 | 1 | 8 | 11 | 4 | 15 | 62.50% | 4 | 3.75 |
| 46 | 0 | 2 | 8 | 8 | 6 | 14 | 58.33% | | 3.75 |
| 47 | 0 | 0 | 1 | 10 | 13 | 23 | 95.83% | 5 | 4.5 |
| 48 | 1 | 0 | 3 | 8 | 12 | 20 | 83.33% | 5 | 4.25 |
| | | | | | | | | | |

APPENDIX F: ROUND 3 MODIFIED SURVEY QUESTIONS FOR FINAL CONSENSUS WITH RESPONDENTS' COMMENTS

| Statement | | Response | |
|-----------|---------------------------------------------|---------------------------------------------------------|--|
| 1. | The Internet can positively impact quality | Comments: | |
| | of health care | Neither Agree or Disagree: | |
| | | Depends on how it is used, it can | |
| | | be negative too | |
| | | Agree: rapid dissemination, | |
| | | linking of patients | |
| | | Neither Agree or Disagree: There | |
| | | needs to be balance | |
| 2. | To optimize consumer safety and | Comments: | |
| | reliability, health-related websites should | Agree but certification should be | |
| | be reviewed and certified | voluntary | |
| | | Agree. Will increase legitimacy | |
| | | and trust | |
| 3. | The Internet enables patients and health | Comments: | |
| | care providers to partner for better health | Disagree. Enables is not the same | |
| | outcomes | as encourages | |
| | | Agree that the potential exists but | |
| | | is not fully realized | |
| | | Agree it makes collaboration | |
| | | possible | |
| | | Agree. Opportunity to share info | |
| | | and connect again | |
| 4. | Responding to patient emails and web | Comments | |
| | requests takes time away from reimbursed | Agree but only if one can't charge | |
| | patient care | for a telephone consult | |
| | | Agree but can be worth the time | |

| 5. | To minimize out-of-pocket health care | Сс | omments |
|----|----------------------------------------------|----|------------------------------------|
| | expenses, patients turn to the Internet for | _ | Disagree. Reasons are multiple |
| | self-diagnosis | | and this is less important |
| | <u> </u> | _ | Disagree. They do it for |
| | | | convenience/privacy |
| | | _ | Disagree. They want input, ideas, |
| | | | referrals mostly |
| 6. | Delays to proper medical care will result in | | Totottals mostly |
| 0. | higher costs to the system | | |
| 7. | The Internet is a primary source for health- | Co | omments |
| ,. | and symptom-related information by | CC | Disagree. Age dependant |
| | | _ | |
| | consumers. | _ | Agree. I agree that it has become |
| | | ~ | the primary and first. |
| 8. | | Co | omments |
| | Internet to communicate with their health | _ | Agree but this is not the major or |
| | care providers | | exclusive venue |
| 9. | Health care professionals can use the | Co | omments |
| | Internet to optimize patient care | - | Agree but other modes are more |
| | | | effective |
| | | _ | Neither Agree or Disagree: Maybe |
| | | _ | Neither Agree or Disagree: Needs |
| | | | balance |
| 10 | . On-line access to certified health care | Co | omments |
| | professionals would be of benefit to | _ | Agree. But without reimbursement |
| | consumers | | it will be fruitless |
| 11 | . Having on-line access to support groups is | Co | omments |
| | of benefit to consumers | _ | Agree if groups are run |
| | | | appropriately |
| | | | |

APPENDIX G: RECOMMENDED STRATEGIES AND POLICIES TO INCORPORATE KEY RESOURCES AND ADVANTAGES OF THE INTERNET

| Panelist | Recommendation |
|----------|-----------------------------------------------------------------------------------|
| 1. | Independent, with standards for independence, i.e. financial relationships are |
| | well laundered. |
| 2. | I suppose sites that are vetted by entities like the Mayo Clinic (a provider) or |
| | a professional organization (like the American College of Physicians) would |
| | be one way to do it. Another would be for a physician to personally review |
| | the site prior to linking it up or endorsing it. Ultimately, there might be some |
| | sort of certifying body that applied a stamp of approval. |
| 3. | It is not possible to restrict patient access to all the information available on |
| | the Internet, regardless of the source. But one can at least direct them in the |
| | right direction by recommending specific sites with additional information, |
| | tools and resources regarding their medical condition(s). Also instant access |
| | to support groups and online certified health care professionals (e.g. |
| | physicians, nurses, PAs, pharmacists, etc) can be of additional benefit. |

4. Standards organizations that validate the accuracy and quality of health care information (they already exist).

Capture of granular consumer data and development of personalization algorithms based on that data that will insure the information delivered is relevant and timely for the individual consumer.

More flexible data privacy rules will need to be developed and implemented.

Use of virtual reality tools (e.g., Second life) will make the use of web more

"fun" for health care consumers.

- 5. There are a wide range of very good, reliable websites. The problem is that they all compete and have different formats. A standardized platform for information that would allow for specific search engines to retrieve the information consistently and in a useable format could be adopted by various societies and organizations.
- A policy or strategy that should be incorporated that lends any of the health care information obtained through the Internet as valid should be related to user identification and password usage. All practitioners should be assigned such access only to sites that have been identified as valid and evidence-based information by the respective health care governing bodies, i.e., the AMA, AOA, etc.
- 7. I think there should be some sort of high level impetus for this. Starting with the federal government there should be groups of people in charge of figuring out how to use the Internet. There should be a hierarchical or tree like chain of command or association down the local level to make sure that

there is uniformity across the country. There should also be a way for the top to listen to the bottom and attend to the flow of information that comes from the front lines. I think that federal money needs to be used, and that starting from the top, interdisciplinary teams should be organized that include knowledgeable policy people, politicians, health care providers and IT specialists.

- 8. Policy leaders should develop a peer review process that tells the consumer that the information that they are viewing is approved by a governing body that they trust. This way it is safer.
- 9. Certain sites have age-appropriate warnings. In this respect, Internet pages that provide medically-related content should be required to have a disclaimer as well. For instance, in the U.S., sites could have the AMA "stamp of approval." Additionally, specific academies of medical specialty, hospitals, or medical universities could approve certain content.

 Additionally, physicians must speak earnestly with their patients above safe use on medical information gleaned from the Internet. Physicians should warn patients about the potential harm that can come from unapproved medicines from other countries or non-scientific based information from the web. Physicians should also recommend specific sites of which they approve for their patients to visit for further disease education.

10. This is the basic scientific question for Participatory Medicine to answer.

It's the new frontier of medicine and the health sciences. It is being asked within the context of a brutally inefficient and unfair health care system that rations care by denying people and families access to the most basic care, creating many unnecessary deaths each years, and causing thousands of people to lose their business and homes. We routinely throw those who can't pay off the life raft, and we favor special interests who engage in medical profiteering over the interests of the public's health and future welfare.

Therefore, it is probably not in the interests of those who currently control the health care industry to use these tools to "ensure safe high-quality health care that incorporates the key resources and advantages available through the Internet," because they are not interested in making health care better, cheaper, or fairer – even without the Internet.

So, my answer is that we must solve the fundamental problems of our health care system, and then use all the tools at our disposal to keep on improving care quality and efficiency. I sincerely believe that health IT care play a role in this effort, but only an enabling role. It will not create justice or by itself alter the balance of power between special and public interest

- 11. People need to know the source of the information for example is the author associated with a pharmaceutical company? there may be some hidden biases in the information
- 12. No Response Provided to This Question
- 13. I can't see any policies which may limit/direct customer to the "right" web

sites as opposed to the non-reliable ones. Education is the key

- 14. 1) Support for information-use training in medical school and residency.
 - 2) Support for global standards of quality and interfacing.
 - 3) Support for better, faster, more intuitive, and more rational interfaces in medical software that are capable of supporting clinical care (as opposed to being designed by architects who are guessing at what constitutes clinical workflow and clinical thinking).
- 15. NA because of response of No
- 16. I don't think this is the role of health leaders. The Internet is an unfiltered resource. It's up to patients to figure out how to use it in a meaningful way
- 17. The main issue is striking a balance between using the Internet for info however not overusing it when it comes to 'medical decisions' that can affect one's health and well being
- 18. As long as they are free from advertising and pharmaceutical marketing or direct to consumer ads, then there could be some benefit added solutions.

 These could entail giving reliable background on their disease and more educational materials, such as self-help advice.

Therefore, they can do homework to reinforce what the provider was trying to tell them as details might have not be comprehended by the patient in the limited time provided.

We can also send reminder or health maintenance messages to patients to get their mammogram, annual exam, etc.

19. Having physicians/medical personnel to oversee or approve such resources

- either in a general or specialty specific \overline{OR} organization specific. like a health IT position
- 20. Again, the current reimbursement structure does not favor the use of these tools, and the level of access is unequal so that those most in need of assistance in managing chronic illnesses usually do not access the Internet.

 Also it is not clear that the 20% of patients that cost 80% of the \$ in the last 6 months of life will be benefited by this strategy, nor is it clear that the system would benefit (cost benefit that is)
- 21. Reimbursement for providers' services over the Internet (e-mail, chat, etc.)

 Secure e-mail for private conversations between providers and patients (and legal safe havens for such communications i.e. for protection against prosecution under HIPAA if someone hacks the communication).

 Legal safe-havens for physicians to make recommendations to people they've never met.
- 22. Since we cannot control who puts information on the Internet, it will be up to physicians, medical societies and public health officials and bodies to maintain accurate information and communicate to patients where to find it.

 With patients having such easy access to information (good and bad), those knowledgeable about what is accurate and good information, and what is not, need to make efforts to educate patients, whether one-on-one or through broader communication such as websites and website links. Perhaps another area could be increased regulation or regulatory enforcement over bad Internet content.

- a. Standardization of electronic records and platforms for integrating patient education/self-management/behavior change interventions into health systems
 - b. Training
 - c. System redesign (that includes patient/family participation)
 - d. Policy change incentives for systems, system change
 - e. Oversight of patient and clinician educational sites to insure quality, up-to-date information
 - f. Link to government agencies that review information (AHRQ, FDA, Surgeon General, CDC)
- 24. There will need to be ways to ensure that Internet sites are reviewed and approved by physicians, specialty societies or another third party agency. I don't want to be overly bureaucratic, but without some way to review, approve and continuously update information to consumers, we run as much risk of disseminating wrong or incomplete information as we do of disseminating good information. Control of an open architecture dynamic system such as the Internet can be difficult and will continue to be a challenge for the health care system
- 25. See reports from the Office of the National Coordinator, Marckle Foundation, eHi, and the 09 Stimulus package, ARRA
- 26. Promotion and funding for open source materials

APPENDIX H: RECOMMENDATIONS OF HOW HEALTH PROFESIONALS COULD BE INTEGRATED INTO WEB-BASED HEALTH INFORMATION

| Panelist | Response |
|----------|-------------------------------------------------------------------------------|
| 1. | I'd have to disclose my secret plan to make a million dollars in order to |
| | answer that. |
| 2. | Especially health librarians, who have a very bright future. But ultimately, |
| | I don't think the health professionals will 'incorporate' the web into their |
| | practice as in turning a switch. Rather, it's already a part of the landscape |
| | and getting bigger and for younger docs that grew up with it, it's |
| | impossible to draw a line. Unfortunately, it's in our blood to create policy |
| | and procedure for everything and I suppose that would be a start here: how |
| | are sites selected, which ones can be recommended to patients, which ones |
| | can be used by health professionals, which ones are linked. But I think |
| | this'll outstrip our efforts to catch up. For example physician 'tweets' and |
| | making them confidential in this age of HIPAA. By the time we figure |
| | that out, another web-based advance will be upon us. |

- A central "go to" health care site that offers information on a variety of 3. common health problems, links to other useful websites, real time assistance with medication questions (e.g. dose, side effects, etc...) provided by a pharmacist and triage of symptoms by a certified nurse, and even direct patient care provided by a physician via the Internet would be of extreme value for certain specialties, especially those that rely highly on laboratory tests and patient history for diagnosis and treatment such as Endocrinology. A site that incorporates social interaction with other patients with similar conditions and also that provides the most up to date, evidence based information regarding not only traditional western medicine, but also health supplements and other medical approaches such as traditional Chinese medicine and a variety of common nutraceuticals. Basically a holistic approach that encompasses the whole patient and addresses all their needs, physical, mental and spiritual, not just the disease itself.
- 4. Health care providers should be educated on the various validated, reliable sources of health care information, and have processes for directing their patients to sites that are relevant to their particular needs. This includes not only information sites, but also support groups, access to information about clinical trials, etc. Providers also will need to become increasingly comfortable with the use of telemedicine, including things such as use of robots for surgical procedures, physical exams, etc.

5. Industry standards and some sort of website certification that structures the content and formatting of the information based on who might be using it would be critical. Doctors, nurses, and pharmacists have different situations in which they need to guide and educate patients. There is no repository of such information, though within disease state websites (often nonprofit organizations), there can be lots of useful information.

We need to assume that specific disciplines may either print or direct patients to specific sites to continue the dialogue. Some capacity for referencing the web content with secure e-mail to the provider would enable ongoing dialogue.

Reimbursement MUST be provided to professionals for this counseling and education. Currently only a few innovative health plans will reimburse for e-mails with patients.

6. As with the evidence-based information above, the same governing bodies need to outline a specific list of sites that are deemed appropriate information for the public at hand to review on the Internet; sites that do not offer conflicts with the current evidence-based guidelines for specific medical illnesses or diseases. Any site outside the identified list would be considered not highly regarded as valid information. Of course, the authors of the site are free to ask the specific governing body for approval on "the list," and if they meet the criteria outlined by the governing body, the site will then become "highly regarded with reputable public information."

Any site not on the list is "enter at your own risk."

- 7. Well, I don't know specifically how, but the general principle would be that people should work in cooperating teams and that an analytical process such as quality improvement ought to be used to gauge the effectiveness of changes made as technology is being adopted. Basically, health care providers need to work with information technology people in an integrated environment.
- 8. Yes. They need to provide incentive to these providers to provide the information. Perhaps a way to bill for the experiences that patient receives.

 This way the providers are compensated for their efforts.
- 9. See answer above[table 8] for ways that providers can participate.
- 10. Great question. It's already happening. Physicians and nurses around the country are engaging with their patients online in e-visits of various kinds, and solving problems and answering questions without the need for expensive travel, for example. I expect to see advances in the uses of personal health record system to guide both physicians and patients toward care that works, and to steer them away from treatments that don't work 11. People need to know the source of the information for example is the author associated with a pharmaceutical company? there may be some

hidden biases in the information

12. This you will have a brighter mind than mine for this one. Doctors are one segment. Actually made up of 62 different clinical subspecialties.

You don't treat them like the doctors they are, and they leave you so fast, you'll still be finishing your sentence. We have doctor websites for chat that you can only get on if you're a doctor. It's great.

Nurses have a different perspective in every way, to a doctor. OR nurses, ER nurses, pediatric nurses.

Pharma, combination of science and business. Basically must make profit. Look at Bayer, almost dead.

Librarians,Jesus, my mom was a librarian. You wanna include librarians? Oh my, well, you definitely need a bigger mind than mine to do that.

- 13. By directing patients to appropriate web sites or by qualifying medical web sites in terms of hierarchal quality
- 14. 1) By making training in medical information use a part of medical (nursing, pharmacy, etc) training at all levels (e.g., medical school, residency, specialty certification, etc).
 - 2) By making web-based information the standard of interchange: hospitals should encourage (or require) web-based interchange of information (e.g., email, etc) within the hospital, between colleagues, and with patients.
 - 3) At the governmental and regulatory levels, we should encourage activities (e.g., e-prescribing) that increase the efficiency and (with due

diligence) the safety of medical care

15. The above-mentioned health professionals could be used to support consumers in need by utilizing their expertise to debunk the pseudoscience and unsubstantiated medical claims diffusely spread throughout the Internet. This can take many forms.

Perhaps the WHO could establish guidelines for online health information/self-help websites.

If sites met the criteria discussed above (well-credentialed authors, peer review/approval, evidence based treatments), the health professionals above will be critical in authoring the articles and directing their patients towards these sites

- 16. It would be better if there was some filtering of the content a consumer reports of sorts for health information. But this would be a huge task that is best handled by the federal government, I think
- 17. Provide a framework that offers enough info to consumers however with prompts that state importance of allowing the health care professionals to be involved in the ultimate health decisions
- 18. A model such as RelayHealth, which provides a compensated medium for interaction without the need for formal visits. In the future, telemedicine will likely play a larger role to keep down the costs of health care
- 19. I think that online boards that allow exchange of information as well as ability to ask opinions over Internet protocols could be useful -with the caveat of TREATMENT shall be initiated and followed by a patient's

personal physician

- 20. The reimbursement model needs to change to make this feasible on a scale that would be meaningful
- 21. Too broad a question. Countless ways
- Health professionals can inform patients where to find reliable web-based information. They should also educate patients regarding all of the potential misinformation that is available.

Most medical societies and health related governmental agencies have websites with reliable and up to date information. This information is provided to the public and is based on sound medical evidence. The more developed, integrated and accessible the network of such web-based information is, the better

23. I think I answered some of these above – there needs to be a host of ways to get clinician input and involvement, in developing and disseminating materials, software, hardware, systems etc.

Also, incentives – payment for e-mail communication; awards for best systems, sites. Sharing stories of benefits!!! Both patient and clinician stories. More research like this!

24. Develop a system to review, approve and make the information consistent with standards of care. Open access by all of the parties above, while simple, may not get the intended results. Open access to develop health care information has the potential to lead to conflicting advice and consumer confusion. I would like to see the Internet become a reliable

| source of patient education and a motivating tool to change behavior, I just | |
|------------------------------------------------------------------------------|--|
| want to be careful that it is done with the best health outcomes in mind | |
| No response provided | |
| Use it as the primary resource for information for patient education | |
| | |