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E-Health: The Benefits & The Potential Risk for a Violation of Patient Information Privacy

Zewdu Shibabaw

GOLDEN GATE UNIVERSITY

E-HEALTH – THE BENEFITS & THE POTENTIAL RISK FOR A VIOLATION OF

PATIENT INFORMATION PRIVACY

CAPSTONE PROJECT

ZEWDU SHIBABAW

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PROFESSOR: JAY GONZALEZ, PH.D

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ABSTRACT

The Internet drives the hottest stocks on Wall Street, shapes technological innovation, and fills the pages of the world's presses. What does this mean for society, government, commerce, and especially for healthcare organizations who are using the virtual world as a vehicle to deliver patient care services through e-Health system.

This proposal compares and contrasts the level advantages and the potential risks involved in providing health care services using e-Health system. The methods used to measure the benefits vs. potential risk on e-Health are the Oakland medical center will be the focus area with the selected groups being patients who are identified and diagnosed with chronic diabetic disease. The study method requires for each selected sample (patient) to respond to nine questions relevant to healthcare services and products provided to the group through the Internet. The collected data will be analyzed to determine benefits vs. potential risk on e-Health.

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INTRODUCTION

With the advancement of Internet technology the way the public does business and communicate has changed drastically. From trading goods to exchanging information, storing and collecting electronic data has become the fundamental part of most businesses (insider-2004). According to e-Health Insider, the ability to access and share patient care information through the Internet can result in several benefits to both clinicians and patients. These benefits include decreased medical errors, decreased collection of redundant data, decreased costs, increased efficiencies, more information at the time patient care is provided and ultimately, improved patient care. (E-health insider 2004)

Use of electronic medical records may also result in a reduction of malpractice premiums; some professional liability carriers provide a professional liability discount for the appropriate use of electronic medical records or for a risk management program that includes electronic medical records. (Insider, 2004, p. 3) For instance, a practice may earn discounts for implementation of an overall risk management program that includes physicians' completion of continuing medical education, office staff training and utilization of electronic medical records. Insurance carrier underwriters may determine that a clinician is at lower risk due to use of electronic medical records or computerized physician order entry, and thus lower that clinician's insurance premiums.

Use of electronic medical records is expected to increase due to pressure

from legislators, business coalitions and consumer advocacy groups (Lohman, 1999, p, 2).

The Internet is a widely accessible source of medical information to patients (p, 4). The present electronic revolution through the Internet has proved to be dramatic but sometimes overwhelming and confusing. Massive amounts of information, both scientific and experimental, can now be exchanged in all directions causing concern about an overload of information that is easy to access but difficult to evaluate. Health professionals are increasingly being drawn into evaluating the Internet as a source of consumer information about health and medicine. Early studies report an estimated 100,000 health-related web sites, and more than 35% of the people using the Internet utilize it for health and medical information (e-Health Insider, 2004). This study proposal discusses the problems inherent in using the Internet for dissemination of healthcare and patient-related information and will share result from data collected and will provide a concluding statement and recommendations based on study findings.

LITERATURE

A search for relevant literature was conducted using the following key words, e-Health, Healthcare, Tele-medicine and electronic medical records. Surprisingly there are hundreds of articles available on e-Health through the Internet. Four articles were selected for literature review based of the following criteria: source credibility, current, factual and scientifically supported information, clarity of analysis presented on the benefits vs., potential risks on e-Health and neutral (zero conflict of interest.)

The following four articles met all the selected method for literature review: *Telehealth: DELIVERING BEHAVORIAL TELEHEALTH VIA THE*

INTERNET (Marlene Maheu, Ph. D. 02/01/00), E-Health: Navigating the Internet
for Health Information *(Jennifer Marconi, May 2002),* Patient-privacy & safe e-
Health *(Marshall,* 2000) and, *Electronic medical record keeping places demands
on IT execs at hospitals (Robert, 2004).* All the four articles provided valuable
information to better understand e-Health, electronic medical records patient
privacy and benefits and potential risk on e-Health.

The first article provided a great deal of information how e-Health
interventions have been shown to enhance healthcare efficiency; improve clinical
decision-making and practice; reduce health services utilization; and lower health
care costs among certain study groups. Most assessments of e-Health
interventions, however, have been limited to small groups that may not be
representative of the parent population, have not been randomized control trials,
had limited follow-up periods, or only assessed proprietary interventions that may
or may not be replicable. According to Maheur (2000) most e-Health developers
do not routinely conduct evaluations, especially post-market assessment for
effectiveness. And when commercial companies and other private sector
organizations do conduct evaluations, the results are often not publicly available.

The second article (Marconi, May 2002) talks about the benefits of
navigating the Internet to access health information and discusses the bridge to
a new healthcare paradigm. Evidence-based medicine provides an explicit
framework of scientifically validated information for medical decision making and
is the cornerstone for a paradigm shift in health care (Marconi, 2002). Evidence-
based medicine supports implementation of cutting-edge programs for health
care management and can lead to improved patient health outcomes as well as
cost-effective care. Yet, despite exponential increase in the biomedical

knowledge base and revolutionary advances in technology, the health care industry continues to rely on a clinical information distribution framework that has changed little over the past century. According to Marconi (2002), we might call this framework the "old paradigm".

The practice of medicine has grown almost unmanageably complex. The limitations of the health care system at the beginning of the 21st Century are such that the old medical care paradigm is less viable and emergence of a new way of practicing medicine is almost inevitable. Four signs suggest that the traditional medical paradigm is not well suited for the 21st Century: non-viability of paper-based systems for supporting clinical care; increasing unreliability of medical practice that depends on human memory; business need for capturing clinical data; and increasing consumer expectations for improved health care.

The third article selected for literature review reveals crucial issues and some of the challenges facing e-Health (electronic medical records). According to Marshall (2000), "People who use the Internet for health-related reasons have the right to be informed that personal data may be gathered, and to choose whether they will allow their personal data to be collected and whether they will allow it to be used or shared." (P, 3) E-health providers should clearly disclose the potential risks to users privacy on the Internet and sites should not collect, use, or share personal data without the user's specific affirmative consent. (P, 5). The article also recommends the two ways "Keep it simple" (Marshall, 200) approach to insure patient privacy: a) Visual: protect health information from being reviewed by casual bystanders, b) Oral: eliminate conversations that involve disclosures of patient health information in public places and, d) Security: implement additional security measures to ensure patient information is not

accessed by unauthorized individual (s).

In addition the articles discusses the challenges transferring years of paper patient records into an electronic format is overwhelming for most physicians and HMO's" (p. 3). According to Marshall (2000, "Investing in an electronic medical record (EMR) is a huge undertaking but one that doesn't have to be overwhelming. (p. 3)

The fourth article talks about the financial benefits of electronic medical records. The use of electronic medical records can result in several benefits to both clinicians and patients (Robert, 2004); these benefits include decreased medical errors, decreased collection of redundant data, decreased costs, and increased efficiencies and, share information. According to Robert (2004), "Use of electronic medical records may also result in a reduction of malpractice premiums." In addition the article talks about some of the professional liability carriers may provide a professional liability discount for the appropriate use of electronic medical records or for a risk management program that includes electronic medical records. For instance, a practice may earn discounts for implementation of an overall risk management program that includes physicians' completion of continuing medical education, office staff training and utilization of electronic medical records (Robert, 2004). According to Robert (2004), "Use of electronic medical records is expected to increase due to pressure from legislators, business coalitions and consumer advocacy groups." The State of California has passed legislation requiring every general acute care hospital, specialty hospital, and surgical clinic to adopt a formal plan to eliminate or substantially reduce medication-related errors.

Collectively all the four articles reviewed for this research suggested that

paper-based health information systems are not a viable long-term option for meeting the changing demands of health care delivery settings. Clinical decision making should be driven by point-of-care information accessed by providers in real time (Maheu, 200, p.3).

METHODOLOGY

The hypothesis for this proposal states that providing healthcare services though e-Health will increase the potential risk for compromising patient information privacy.

The independent variable is e-health as a means to provide healthcare services, with the dependent variable being the potential risk for patient information tampering and or, misuse by unauthorized personnel. The key purpose of this hypothesis is to measure advantages vs. disadvantages and clearly understand the potential risks involved with e-
Health system.

Operational definitions:

For this study the term e-Health will represent the application of Internet principles, techniques and technologies to provide healthcare services. The term electronic medical record will represent the application of Internet technology to store, share and update patient care information electronically.

Target Population and Sampling:

Considering the abundance of e-Health initiatives by small and large HMO's throughout the nation (*e-Health initiative, p. 5*), it was determined to focus on a specific healthcare origination and selected group (population) within the sleeted healthcare system. *(Dr. Roper, 2004).* Looking into following criteria's: data availability, reliability of information source, proximity to survey / interview &

access and permission to collect sensitive patient care data on a selected group, Kaiser Oakland was selected with targeted population being current health plan members who are identified as chronic diabetic patients. A survey questionnaire (Appendix A) was developed to collect data directly from existing Kaiser Oakland medical center members who are identified as chronic diabetic patients. The total population of this group is 200; sample size selected and provided survey questions to collect data was 100.

Data collection rules:

a) All the samples (patients) within the selected group are to be informed their patient rights and the purpose of this study in its entirety thereby, can refuse participating.

b) The study data can only be collected from the selected group

c) Survey method: Phone call.

d) The collected data can't be used for any other purpose other than this proposal.

After contacting each patient within the selected group, the participants were asked to answer nine questions with the following options: Yes, No and, No comment (Appendix A). The "No comment" option was specifically added to give alternatives for the sample group (patients) that may refuse to participate throughout the entire data collection process or refuse to answer a specific question. (The Patient's Bill of Rights, 1992, pp. 5-6). Findings

RESULTS & FINDINGS

The type of question and percentage of response given was aggregated for all the data collected from each patient. Following the methodology the data was collected only from 100 survey samples out of the existing 200 population

(Oakland medical center health plan member who are identified as chronic diabetic patients.)

From the collected data result it was identified that 100% of the participants were within the targeted sample group. Further, result from the survey indicated that 60% of the participants either don't have access to the Internet or have a computer. A question was also presented to determine if the participant's used the Internet to access health information or make appointment with their personal provider, only 50% said Yes, 45% said No and, 5% with No comment. In addition the participants were asked if Kaiser's new electronic medical record system has improved their experience with their provider, 70% said Yes, 20% said No and, 10% said No comment.

COLLECTED DATA RESULT
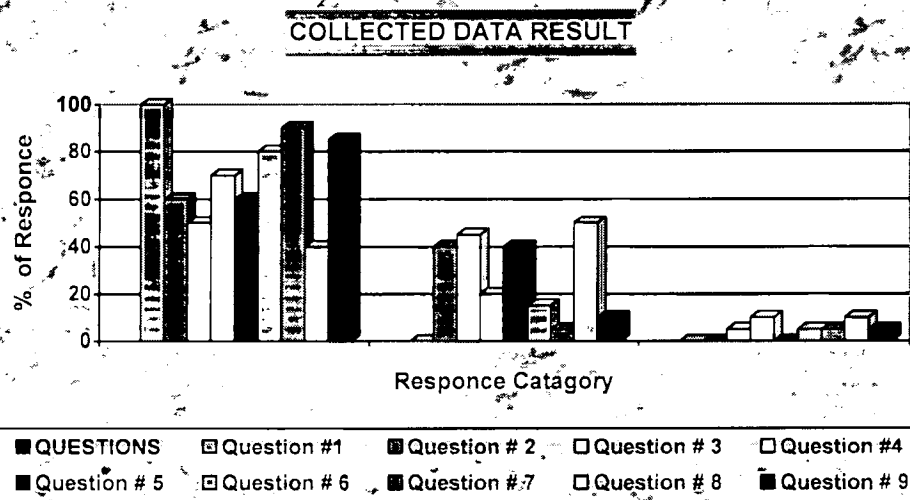
For this group one of the crucial questions may have been the ability of e-Health to manage effectively patients who are diagnosed with chronic diabetic and, 60% of the sample said Yes, and 40% said No. With respect to the general safe record keeping on e-Health, surprisingly 80% said yes, 15% No and, 5% said no comments. To emphasize the research proposal on the selected healthcare organization and targeted population, the participants were asked, if

they believe that Kaiser's newly implemented e-Health benefits outweigh the potential risk involved for patient information privacy, the results was astounding 90% said Yes, 5% No and with 5% No comment.

Though the results indicates Kaiser's e-Health system has a greater benefits than its potential risk, 50% of the participants didn't believe that Kaiser has a secured system to maintain patient privacy and stated their concerns for the potential tampering or misuse of personal health inform on the Internet.

A unique question was also presented for the participants to determine if they are satisfied with the level of service and quality of care provided by Kaiser Permanente since the implementation of the new e-Health system. Surprisingly 85% of the participants said yes, 10% said No and, 5% said No comment. The results of this study further suggests reexamining the following three crucial issues with the implementation of e-Health and recommending a policy to ensure efficiency (patient satisfaction), ethics and, patient privacy play a fundamental role in e-Health.

CODE OF ETHICS

Physicians need to consider several ethical and legal issues before engaging in online consultation and communication with patients. While it is prudent to be familiar with the relevant laws of your state, the law may not always be up-to-date on current practices vis-à-vis the Internet.

The e-Health code of ethics is an important part of the effort to make it possible for the Internet to realize its potential to enhance people's health status and well being world wide (Wiley, 2004). The goal of the code is to help create a trustworthy environment for all users, whether they are patients, health care professionals, and website sponsors, people who develop health applications and content for the Web or individuals that turn to the Internet to help them stay

well. Health information and services provided over the Internet have the potential to improve health as well as to do harm. Organizations and individuals that provide health information on the Internet have obligations to provide high quality content, protect users' privacy, and adhere to standards of best practices for online professional services in healthcare. According to Robert, "The goal of the e-Health Code of Ethics is to ensure that people worldwide can confidently, and with full understanding of known risks, realize the potential of the Internet in managing their own health and the health of those in their care. (Robert, 2004, p. 6) satisfaction

EFFICIENCY & PATIENT SATISFACTION

For this study patient satisfaction is measured on the scale of 50% or greater being an indicator for e-Health benefits exceeding the potential risk on patient satisfaction survey. This study shows 85% of the patients are satisfied with the level of service and quality of care provided. Obviously consumer behavior in healthcare has undergone significant changes since the emergence of Internet technology allowed patients to take charge of their health. (The role of e-commerce in health care, 2003, p, 4) As such, a new, informed, and empowered patient evolved and along with this evolution there were new demands and expectations placed on the healthcare industry to improve
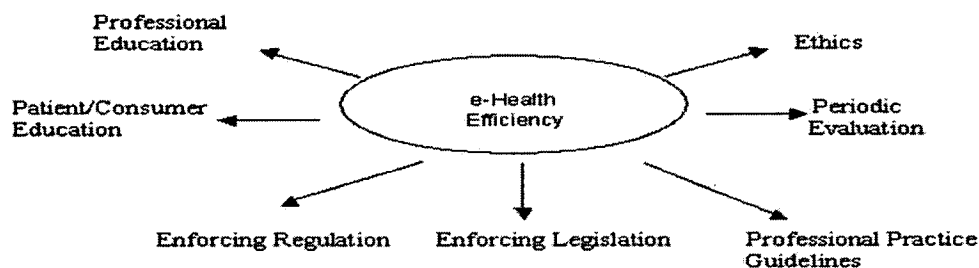
Figure 1. Efficacy of Electronic Health Information

(e-Healthcare, 2003)

They key benefits of e-Health is patient self-service transactions and online communication can increase practice efficiency and productivity through fewer telephone calls, decreased administrative costs, and growth through attraction of new patients (Marconi, 2002, p. 3) One result of increased practice efficiency would be that more office visits could be reserved for, as well as physicians dedicating more of their time to those patients truly requiring face-to-face care. A good example some of the administrative and clinical functions previously handled only by telephone or face-to-face encounter that can now be accomplished through secure communication include:

a) Administrative: appointment requests, update information, online medical payment and, non-clinical patient inquiries.

b) Clinical: Rx renewals, test results, uploading data from home monitoring devices with clinical feedback and d, non-urgent e-consults.

MEDICAL DATA PRIVACY

For this proposal the term Patient Privacy is defined as a sacred heart e-health providers must maintain the privacy of personal health information.

Today, individual health and medical data can be collected, collated, stored, analyzed and distributed in unprecedented quantities over the Internet and put to diverse uses for the ease of medical practice (Reid, 2004). Providing health care services and products through the internet has the potential both to improve health and health and to do harm, organizations and individuals that provide health information on the Internet have obligations to be trustworthy, provide high quality content, protect users' privacy, and adhere to standards of best practices for online commerce and online professional services in health care.

In addition, e-Health providers should fully comply with the newly enacted Health Insurance Portability and Accountability Act of 1996 protocols protecting patient records. (HIPPA,1996 Act). The role of e-Health in the process of providing patient self-service and secure communication can be addressed from both the patients and physicians perspective. The bottom line is that providing patient self-service and secure communications has more to do with financial, organizational and communications factors than it does technology factors. E-health is not the solution, but instead a key enabler (Barnes, 2003, p. 2).

SUMMARY & CONCLUSION

This study result indicates that the Internet is changing how people view health information and health care services. 85 % of the participants for this study expressed a great deal of satisfaction with e-Health and expressed the effectiveness of Kaiser's e-Health system to interact with their primary physician enabling them to reduce the drive and parking hustle to the Oakland medical center for a routine appointment or a simple physician consult.

One of key benefit observed with this study group was, being a chronic diabetic patient the group has increased need for medication refill and routine checkup with their primary physician, 70% of the group expressed the increased quality of care and the ability to request refill prescription drugs online. The result from this study indicates also indicates increased concern when it comes to patient information privacy. For example 80% of the participants for this study don't believe their health information is safe and secured on the Internet. "Patients use who use the Internet for health-related purposes patients, health care professionals and administrators, researchers, those who create or sell health products or services, and other stakeholders must join together to create

a safe environment and enhance the potential risk involved with the of the Internet." (Paul, 2004)

Considering the potential risk for patient information privacy, Kaiser has implemented a security measures that will allow health plan members to change or create a new password, if they suspect unauthorized individual may have accessed their private information. From this study its clear that patients who use Internet health sites and services share a responsibility to help assure the value and integrity of the health Internet by exercising judgment in using sites, products, and services, and by providing meaningful feedback about online health information, products, and services.

Although technological advancements in science have greatly improved medical care in recent decades, improvements in the management the privacy of patient information has been a challenge (Barnes, 2003). The disadvantage with the paper based medical record is, the task of retrieving patient records, extracting and adding new information, and returning these records to their appropriate place of storage each day was burdensome, managing the information in the records was even more tedious.

One of the key advantages with health information electronically is that information can be accessed, updated or shared faster to make effective clinical decisions that will benefits the patient. On any given day a Kaiser physician, nurse, health information management personnel data managers can review the same information from different locations electronically to make ethical decisions that will enhance the quality of care provided. However, prior to e-Health it was necessary for the medical record to follow the patient throughout their visit.

This study supports that the Internet offers an unprecedented opportunity

for healthcare information to be disseminated instantaneously. Quality of information, both scientific and nonscientific and the development of tools to disseminate information securely via the Internet are the two most important issues related to achieving effective and wider exchange of health information. For the first time ever, information can be exchanged simultaneously and interactively all around the world, with the potential of being equally available to healthcare professionals as well as to patients.

For the participants of this study the big difference between yesterday's paper-based health care service and that of today's electronic medical records system is, patients are able to explore the web world with a desire to learn more about their specific diagnosis and condition, including alternative treatments on the market. This has evolved into the reality of today's e-Health system.

THE NEED FOR FURTHER STUDY & POLICY RECOMMENDATIONS

The study indicates that the Internet and related new communication technologies enable health professionals to reach large populations with interactive applications, which in turn opens enormous opportunities and challenges. The need for further research and policy recommendation is a must to ensure the public is provided quality healthcare without compromising individual health information privacy on the internet (e-Health). Cyber medicine research should go beyond mere development and provision of technical solutions; it should also address social and human factors, and evaluate the impact of the Internet on society and health care, and public health. As a Public Administrations student, I have the responsibility not to follow blindly the general Internet hype but to help physicians and consumers to maximize the use of the

Internet by carefully evaluating the interventions and revealing determinants that influence effectiveness and efficiency of Internet communications in health care.

POLICY RECOMMENDATIONS FOR ADVOCACY GROUPS & TIPS FOR THE CONSUMER

It is my recommendation that the consumer / the public should follow the following key steps when utilizing the internet for healthcare services.

1. Choose sites you can trust:

a) Look for Seals of Approval. There are several important efforts to help assure quality in provision of accurate, up-to-date information in the fields of health and medicine. These include the Health-On-The Net Foundation (HON), Hi-Ethics, and the IHC Code. Sites that reference one or more of these seals have a better chance of providing reliable information.

b) Look at who is sponsoring the site. As yourself questions like: Is this site trying to sell something? Do healthcare professionals review the information? How often is the site updated? If you are unsure who pays for the site, look for another one.

c) Look for sites linked with major medical centers and groups, government agencies, medical professionals or major publications.

d) If you need information about a specific subject, look for trusted sites that specialize in that area or provide more information in that area than others.

2. Ask around:

a) Go to an online discussion forum and ask about various sites. Fellow consumers are often a good source for the latest and best references. Some Web sites, like omez.com or twirlix.com offer ratings of online health sites.

b) Get a second or third opinion. For important health information, visit more than one Web site. Even the best doctors can disagree on appropriate treatments.

c) Always ask your doctor's opinion about specific medical conditions. Don't forget, Web sites exist to better educate you, not take the place of a licensed health professional.

3. Watch out for quacks:

a) Be wary of sites touting miracle cures or revolutionary therapies. If it seems too good to be true, it usually is. Especially keep an eye out for pseudo-medical jargon. Don't buy into promises to "detoxify" your body or "balance" its chemistry. These concepts are virtually impossible to measure.

b) Be wary of any sites that say that most diseases are caused by faulty nutrition or can be remedied by taking supplements. Some diseases are related to diet, but most are not. And when they are, the solution usually isn't to take vitamins, but to alter the diet. Also, keep in mind that most herbal remedies are promoted through hearsay, folklore and tradition. Most herbs contain hundreds of chemicals that have not been completely catalogued. And, while some may turn out to be useful, others could be toxic.

c) Unfortunately, many sites contain outdated, erroneous or biased information, while others are designed primarily to sell services, products or drugs. Major non-commercial sites have the following domain assignments at the end of their names:

- .edu (educational and university-based medical institutions);

- .org (usually non-profit membership or voluntary organizations);

- .gov (government agencies and organizations);

- .mil (U.S. military)

Regardless of who their sponsors or supporters may be, health and medical-related Web sites should openly identify online advertising and disclose all financial relationships. Avoid sites that appear to be focused merely on selling a specific product or service. Look for sites that provide unbiased health information.

JOIN ONLINE PUBLIC ADVOCACY / SUPPORT GROUPS

Many consumers have found valuable assistance and support from online discussions forums among people who share similar health interests or conditions. Online support groups serve as news and information-sharing areas that provide specific information and/or mutual support for those afflicted with similar health problems or emotional losses. These support groups are usually organized on a volunteer basis and offer their services free of charge. Support groups can be very helpful and well intentioned. Nevertheless, care should be taken when selecting and participating in such groups. There is virtually no oversight on these groups, and claims and statements made by members may be false and/or exaggerated. They also may be sources for misinformation or unscrupulous schemes.

UNDERSTAND THE RISKS OF CONNECTING
(OPEN SYSTEMS INTERNET)

Linking computers together means that you can access other people's data, but it inevitably follows that this allows others to access data on your own system. Until such time as individual computers or networks are linked together

they resemble `islands' of electronic data. Security on a data island is simple: reassuringly firm borders trap all unauthorized entrants. However, when you build bridges by creating a network link this approach on its own is inadequate. When a computer connects to the Internet, it loses its island status by compromising the integrity of its `borders'. Any potential benefits of connecting must be weighed against the risks to your own data. In a healthcare environment, this data is often of a highly sensitive nature. Even connecting a home computer may expose data, such as banking details, which you would prefer to remain private

THE ROLE OF CONSUMERS:

Today, a large number of patients and consumers already use the Internet to retrieve health related information, to interact with health providers and even to order pharmaceutical products. Physicians mainly use the web to access databases such as Medline or to read electronic publications, but in many parts of the (developed) world they clearly lag behind other professions in their use of modern information technology instead, consumers have taken the lead in adopting the new media for retrieving and exchanging health information. Informed and Internet-savvy patients will play a crucial role in being a major driving force for clinicians to 'go online' and for evidence based medicine: Consumers accessing online information will inevitably increase the pressure on care givers to use timely evidence, and will encourage them to acquaint themselves with information technology to deliver high quality health services. For the first time in the history of medicine, consumers have equal access to the knowledge bases of medicine and they are making heavy use of this: It has been noted that "the number of Medline searches performed by directly accessing the

database at the National Library of Medicine increased from 7 million in 1996 to 120 million in 1997, when free public access was opened; the new searches are attributed primarily to non-physicians". Thus, the Internet will act as a catalyst for evidence based medicine in two ways: First, it enables health professionals to access timely evidence. Second, it enables consumers to draw from the very same knowledgebase, leading to increased pressure on health professionals to actually *use* the evidence.

INTERNAL POLICY RECOMMENDATION

TO-KAISER PERMANENTE BOARD OF DIRECTORS

Providing personal health information over the Internet can expose consumers to possible invasions of their privacy. So, it is important, prior to communicating any personal data, to carefully review a site's privacy policy. Not only should a site provide users with reasonable notification of its information practices, it should also enable consumers to accept or decline collection of data, and allow them to give their consent before transferring information to third parties. Avoid sites that do not provide privacy statements, offer only an ill-defined code of privacy, have open-ended statements regarding the sharing of information with affiliates, or maintain unacceptable tracking procedures that identify visitors to the site. Look for sites that readily display their privacy policy up front, and subscribe to a privacy code of ethics like "Verisign" or "Trust-E."

Kaiser being one of the largest non-profit HMO in the Nation, Kaiser has the responsibility both to improve the public's health service and while maintaining individual privacy. All people who use the Internet for health-related purposes must be able to trust that Kaiser's healthcare sites they visit adhere to the highest ethical standards and that the information provided is credible.

Because health and health care are critically important to people, the organizations and individuals that provide health information on the Internet have special, strong obligations to be trustworthy, provide high quality content, protect users' privacy, and adhere to standards of best practices for online professional services in health care.

GUIDING PRINCIPLE:

Kaiser Permanente and its Board of directors should mandate the entire medical staff (Physicians, Nurses & support staff) who are providing health information, products, or services on the Internet to Kaiser's healthcare members to follow the following principles:

1. Quality

a) Provide high quality information, products, or services

b) Provide means for users to evaluate the quality of health information

2. Best practices for provision of health care on the internet by Kaiser's health care professionals:

a) Adhere to the highest standards of professional practice

b) Help patients to understand how the Internet affects the relationship between professional and patient while adapting the highest professional standards to the evolving interactions made possible by the Internet.

c) Alert users to the potential risks to the privacy of personal information on the Internet (for example, that third parties may be collecting information without the site's knowledge).

d) Clearly describe the accountability mechanism used by the organization or site and how to contact the responsible party.

e) Culturally appropriate and easy to use.

f) Accurate, unbiased and, up to date health information.

3. Informed Consent, Privacy & Confidentiality

a) Safeguard users' privacy

b) Obtain users' informed consent when gathering personal information Informed Consent to make prudent decisions about whether to provide personal information online, especially information about their health status, people need to know what information is being gathered and why. The personal information that may be gathered by a health-related site is often intimate and highly sensitive. People must be able to trust Kaiser as a health service provider that their personal information will be kept confidential and secure. Thus:

a) Prevent unauthorized access to personal information

b) Assure users' access to their personal information

c) Assure users' rights to review personal information and to amend it as appropriate or necessary

d) Provide mechanisms for tracing use of personal information (for example, audit trails)

e) Prominently, clearly, and accurately identify the business and/or site sponsors

f) Clearly distinguish content intended to promote or sell a product, service, or organization from educational or scientific content.

g) Clearly disclose any financial or other incentives for providers who develop or present content

4. Principle & Truthfulness

People using the Internet for health-related purposes need to know that products or services are described truthfully and that information is accurate and reliable. Thus, organizations and individuals who sponsor, promote, or sell health

information, products, or services on the Internet have an obligation to tell the truth; tell the whole truth; make sure it is the truth.

The leaders within Kaiser Permanente have the ultimate responsibility to ensure health care professionals within the organization such as, Physicians, nurses, pharmacists, therapists, and all other health care professionals who provide information, products, or services pertaining to an individual's health care on the Internet have fundamental ethical obligations to respect and maintain the public's privacy while providing quality health care services.

POLICY RECOMMENDATION ON THE UNITED NATIONS LEVEL

On the Internet, information and communications flow unimpeded across national borders. The Internet places the corner store, and a store three continents away, equally at the individual's fingertips. Just as the flow of personal information across national borders poses a risk to individual privacy, citizens' ability to transact with entities in other countries places individual privacy at risk in countries that lack privacy protections. National laws may be insufficient, on their own, to provide citizens with privacy protections, across borders. Whether it is protecting citizens from fraud, limiting the availability of inappropriate content, or protecting privacy, governments are finding their traditional ability to make and effectively enforce policies challenged by the global communications medium.

Today, the Internet is revolutionizing healthcare by providing a wealth of information and resources about health, health services and products. There are currently as many as 55,000 sites online that offer information on health and medical care, and hundreds of thousands of Web pages dedicated to a broad range of topics

Medical Informatics Ethics
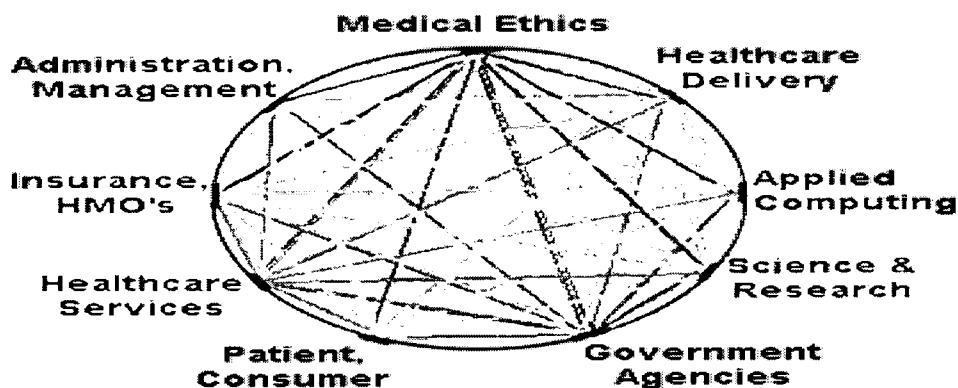
While developing appropriate domestic policy may be sufficient in a paper-based world or a centralized and closed network, where nations can control the flow of information about citizens thereby protecting them from areas where protection is insufficient, information in a networked environment flows effortless from country to country, organization to organization, and policy regime to policy regime. Effective monitoring of the generation, collection, and flow of information on this vast scale may tax the resources of those currently responsible for data protection or other policies.

In addition to the difficulty of enforcing rules, governments around the globe are struggling with how to develop appropriate and effective rules. Efforts to use legal and regulatory instruments developed to address issues in other media broadcast, telephone, and print may not be effective, and in cases like the United States' Communications Decency Act, may be found impermissible. The need for global, decentralized solutions has prompted various international bodies including the European Union, the Organization for Cooperation and Development, and the United Nations to examine how to best advance their missions in this new environment.

Privacy and the legal aspects of the information superhighway, is proven to be very difficult to govern in the way that the United Nation (UN) may wish.

However as a Public Administration student and a concerned citizen, I am recommending the following policies to be implemented and enforced at the United Nations level:

a) Establish global internet rules and regulations and implement technologies that give individuals control over personal information during commercial interactions.

b) Adopt enforceable standards, both self-regulatory and regulatory, to ensure that information provided for one purpose is not used or disclosed for other purposes. At the same time the UN must recognize that in this freewheeling and open global market, there will be limits to the effectiveness of regulation and self-regulation. Therefore, the UN must look to technological tools that will empower citizens to control their personal information.

c) Encourage technologies that limit the collection of personally identifiable data without the public's knowledge or permission Law is only one tool for protecting privacy. In this global, decentralized medium, we must promote applications of technology that limit the collection of transactional information that can be tied to individuals. Some tools developed to protect privacy by limiting the disclosure, or cloaking it, of information likely to reveal identity, or decoupling this identity information from the individual's actions and communications, exploit the decentralized and open nature of the Internet

d) Create a privacy protection entity to provide expertise and institutional memory, a forum for privacy research, and a source of policy

recommendations on privacy issue. To function well, such an entity should have the ability to:

- monitor and evaluate developments in information technology with respect to their implications for personal privacy;

- Conduct research, hold hearings, and issue reports on privacy issues in both the public and private sector.

- Develop and recommend public policy appropriate for specific types of personal information systems globally.

- Comment upon government and private sector proposals that impact on the global community privacy issues.

- Review agency activities under the Privacy Act.

- Participate in countries and, government proposals that impact the public's privacy globally.

THE U.N SHOULD REGULATE & MONITOR ONLINE DRUG COMPANIES GLOBALLY:

A growing number of Web sites sell prescription drugs directly to the consumers, who can order from home, often at discounted prices. In fact, almost all of the major retail pharmacy chains are affiliated with an Internet site that offers online sales. Reputable sites require that prescriptions written by a patient's health provider, and adhere to regulations enforced by government agencies such as state pharmaceutical boards in the United States. But prescription drugs also can be bought at sites located in other countries, where there are few, if any, laws or enforced policies. Consumers should stick with well-recognized sites affiliated with known pharmacies, or those that adhere to recognized industry self-regulation mechanisms such as the Verified Internet

Pharmacy Practice Site or "VIPPS," run by the National Association of Boards of Pharmacy. In some cases, sites offer brief medical "consults" with their own health care professionals who then order prescriptions for consumers. Others sites simply require completion of a request form and a disclaimer that waives the site's liability for any adverse results from use of the drug. These sites should be avoided since they do not follow basic ethical procedures recognized by most regulating agencies.

Before purchasing prescription drugs online, the public should be informed and consider the following:

- The U.N should make it illegal for doctors to prescribe drugs for patients in a states or countries where they are not licensed to practice. This is more serious when such prescriptions are not made based on a proper medical examination and knowledge of co-existing conditions and related medication use.

- The U.N should prohibit purchasing on the e-Health (Internet) without a licensed physician's prescription (a physician personally familiar with the patient's condition(s) and history). The review of on-line questionnaires by the host's staff physicians should not be sufficient basis for obtaining a prescribed drug.

- The U.N should prevent purchasing or selling prescription drugs that are not yet approved by the U.N. Food and Drug Administration for sale

POLICY RECOMMENDATIONS FOR STATE & FEDERAL GOVERNMENT

Organizational Policy; Privacy.

Federal & State Government Should Monitor Viruses:

Viruses are small segments of code that have been inserted into computer files, often with malicious intent. An infected file may cause annoyance or the loss of data. In theory, any file you download from the Internet is a potential vector. Viruses may also be present in files attached to e-mail messages (but cannot be transmitted via a text-only e-mail itself). There are a number of antiviral programs available (some are free) that will screen for and help you neutralize infected files on your computer-- before they are activated or have a chance to `replicate'. Some viruses are activated when you use an infected program; others merely require you to view an infected document. Antiviral programs act like the body's immune system in that they are always on the lookout for `foreign' material--in this case, foreign program code. However, even if your software is regularly updated it won't catch all viruses (especially new ones). Security should be based on the sound sense of not opening e-mails from unknown sources or those containing unusual message headers.

The protection of personal data in a connected world defaults not so much to high-tech applications or hardware, as to careful management of staff and relatively common techniques to ensure the simple, frequent risks are catered for. The determined criminal or government agency will get access somehow, but what matters to doctors is making sure that we take care of the data we collect about patients in a manner appropriate to the twenty-first century.

Regulating Medicine on the Internet:

The evolution of the 'information age' in medicine is mirrored in the exponential growth of medical webpages, increasing number of online

databases, and expanding services and publications available on the Internet. The handful of computers linked by the predecessor of the Internet in 1969 has grown to more than 5 million websites today, of which at least 100,000 have health-related content. More than 150 million people currently communicate over the Internet. Medical information is among the most retrieved information on the web. Health information providers on the web mostly include private companies offering medical products or medical information, individual patients and health professionals, patient self support groups and professional associations, non-governmental organizations, universities, research institutes and governmental agencies.

Policy Recommendation for State & Federal Government to Regulate Quality of Medical Information:

The often poor quality of information on the Internet is a potential limiting factor for the usefulness of the Internet for both consumers and health professionals. Studies assessing the quality of health related websites, newsgroups or evaluating interactive venues using the method of posing as a fictitious patient have demonstrated that important aspects of quality like reliability, accessibility and completeness of information and advice on the Internet are extremely variable. While this problem is also known to happen in traditional media like magazines, newspapers, and television, the Internet creates additional problems, such as the originators of messages and their credibility are difficult to assess by readers. Solutions for these concerns such as the widespread use of evaluative information have been proposed and will, once adopted, help to make the web a more useful tool for patient education. Furthermore, the Internet will open new ways for professional medical education.

State and Federal Government should Regulate Fraud and Abuse Health Web Sites:

The proliferation of medically focused web sites on the Internet has been nothing less than dramatic. Web sites serve as dynamic, interactive devices for the provision of health care services to consumers. This "e-health" commerce offers numerous benefits to consumers, including obvious convenience, low barriers to entry and the elimination of geographic boundaries. These same characteristics which define Internet e-health commerce are also giving rise to increased scrutiny by government enforcement agencies which have taken note of this revolution in health care. Concern has grown that consumers may subject themselves to misinformation and that providers may use this information technology for fraudulent purposes.

The U.S. Department of Justice (DOJ) has started to expand enforcement activities in matters related to e-health web sites for both the Health Care Financing Administration (HCFA) and the Food and Drug Administration (FDA). The DOJ has made it clear that combating fraud and other white collar crimes particularly those which target the elderly and other vulnerable consumers and those targeting taxpayer-funded health care programs is a DOJ priority. In 1999 the DOJ collected $524 million in criminal fines, civil settlements and administrative penalties. Further, this health care enforcement activity is expected to intensify significantly in coming years thanks to increased dedicated funding for this activity. The budget for fiscal year 2000 is $158 million and in fiscal year 2001 the figure will increase to $240 million. Enhanced resources means more investigators, auditors and prosecutors focused in health care fraud of all types—including Internet fraud. Health care providers should take particular

care when structuring e-health ventures in that existing federal fraud and abuse provisions apply with equal force to e-health commerce.

Enforcement of Federal Anti-Kickback Statute:

The Federal Anti-Kickback Statute is a federal criminal statute that generally proscribes the offering, payment, solicitation or receipt of any remuneration in exchange for referring an individual to another person or entity for the furnishing, or arranging for the furnishing, of any item or service that may be paid for in whole or in part by Medicare, Medicaid or other federally-funded health care programs. Illegal payments (or offers or solicitations of payments) include those in cash or in kind, those made directly or indirectly, and those made overtly or covertly. In addition to criminal penalties, violation of the Federal Anti-Kickback Statute could result in civil monetary penalties and exclusion from the Medicare and Medicaid programs.

Because of the potential applicability of the Anti-Kickback Statute to many common and necessary business transactions in the health care industry, as required by Congress, the Office of Inspector General, (OIG) has promulgated a number of so-called "Safe Harbor Regulations" identifying business relationships that would not subject the participants to criminal or civil prosecution. The failure of a business relationship to meet the requirements of a safe harbor does not necessarily mean that the relationship is violative of the Anti-Kickback Statute, although there would be some risk that such a relationship could be found to violate the Anti-Kickback Statute. Where a business transaction does not meet the requirements of a safe harbor, the legality of any particular arrangement will be determined by comparing the particular facts of the transaction to the proscriptions of the Anti-Kickback Statute.

No Anti-Kickback Statute enforcement actions have been brought to date which involve physicians and other providers who furnish medical items or services over the Internet, but given the proliferation in the number of Internet sites, the number of potential referral sources involved in these arrangements, and the increasingly aggressive health care fraud and abuse environment, it is only a matter of time before enforcement actions commence. For instance, an area of government focus could well be the financial arrangements between a medical web site sponsor and the providers or suppliers who advertise on that web site. If a medical web site sponsor solicits fees from these advertisers or sponsors, who either directly or indirectly provides goods or services billed to Medicare as covered services, this revenue source raises the question of whether any payments made by advertisers or sponsors to the web site might be considered a violation of the Anti-Kickback Statute. To the extent that such fees vary based upon the volume or value of Medicare services furnished by the provider or supplier to the web site sponsor, the government could take the position that the Anti-Kickback Statute is implicated.

Enforcing the Stark Laws:

The Stark Laws generally prohibit a physician from making a referral to an entity with which the physician has a "financial relationship" for the furnishing of "designated health services" for which payment may be made under the Medicare or Medicaid program, unless one of several enumerated exceptions applies. The term "financial relationship" is defined broadly to include any ownership or investment interest of a physician in an entity or any compensation arrangement between a physician and an entity. More specifically, compensation

arrangements encompass any form of remuneration between the two parties, whether direct or indirect, in cash or in kind.

Similar to the Anti-Kickback Statute, the Stark Laws have not been enforced in an e-health context. However, examples of potential enforcement readily emerge. For instance, consider the following scenario: a physician practice establishes a web site to furnish consultations to patients over the Internet, and allows a durable medical equipment (DME) supplier to advertise on the site. Under that circumstance a "per click" advertising fee would likely not be permissible because the fee would relate to the volume of referrals. The physician practice would also be prohibited from ordering Medicare-covered DME equipment from that supplier for a Medicare patient accessing the site unless the financial arrangement between the DME supplier and the practice were to fully satisfy an exception to the Stark Laws.

FDA Enforcement:

In partnership with the FDA, the Federal Bureau of Investigation and the Drug Enforcement Agency, the DOJ is focusing on e-health companies and ventures that sell or promote drugs or medical devices on-line. The FDA has indicated that it believes it has jurisdiction under the Food, Drug and Cosmetic Act, because there is a federally mandated requirement of a physician-patient relationship that is a prerequisite to a valid prescription. The FDA has issued warning letters to approximately twelve international Internet sites, and has indicated that it is investigating sites based in the United States as well.

In May 2000, in federal hearings before the House Commerce Subcommittee on Oversight and Investigations, an FDA official stated that the agency has performed at least a cursory review of 400 web sites and has 54

sites under active review for possible regulatory or civil actions. Additionally, the FDA has sent 38 warning letters to online sellers from its Office of Compliance. Lastly, the FDA's Office of Chief Counsel has sent 17 "cyber letters" to proprietors of foreign-based Internet sites that sell prescriptions online. (Cyber letters are sent via the Internet to suspect web sites, warning that they may be engaged in illegal activities). At these same hearings, the DOJ testified that it has filed several cases involving drug sales via the Internet this past year, about 20 of which involve Internet drug sales, some for fraud against individuals who distributed drugs in interstate commerce without a prescription.

The White House should Support FDA Proposal:

On May 2, 2000 the White House unveiled legislation to Congress, titled the Internet Prescription Drug Sales Act of 2000 which would provide additional oversight powers to the FDA by amending the Federal Food Drug and Cosmetic Act to require online pharmacy sites to be licensed in each state in which they operate or in which they sell prescription drugs. In essence, the underlying goal of the proposed legislation is to ensure that online pharmacies are licensed and operated under the same regulatory system that Congress and the States have put in place for traditional "brick and mortar" pharmacies. The proposed legislation, among other things, calls for online pharmacies to post information on their web sites about their ownership and state licensure.

The proposed legislation would also provide the FDA with civil and criminal subpoena power over the Internet pharmacy sites and allow for the FDA to levy civil fines of as much as $500,000 against online pharmacies violating the licensure requirements. There is no doubt that the Internet and e-health commerce will continue to transform the practice of medicine. Those physicians

who venture into this evolving marketplace are well advised to remember that, although the regulation of e-commerce will likely continue to lag behind the marketplace, many of the same fundamental fraud and abuse legal restrictions which apply to paper commerce and "brick and mortar" ventures currently pertain to e-health commerce. Therefore, appropriate legal advice should be obtained before entering into this brave new world.

In conclusion, given the variety of confidentiality requirements and initiatives at both the state and federal levels, e-health businesses should institute safeguards to protect the confidentiality and integrity of patient information transmitted through the Web or other electronic means, e-Health businesses need to be sensitive to their potential liability risks for the public's safety and privacy of information. For example, if doctors who do not have access to a patient's complete medical record and who have never personally examined a patient interpret and provide advice based solely on a patient's description of his or her own maladies or on diagnostic tests transmitted over the Web, the services may well be deemed to be inconsistent with the standard of care prevailing in the community where the patient is located. E-health marketing and advertising should be also subjected to regulation by the Federal Trade Commission and, where medical devices or pharmaceuticals are concerned, by the FDA. E-health businesses face the same panoply of legal issues as other dot.com and technology ventures and then some. Paying proper attention to the health-care specific issues can spell the difference between a successful venture and one that ends up in a legal quagmire.

FUTURE PERSPECTIVE

The Internet will not be the same in the next millennium. Important developments are likely to improve not only the speed (Next Generation Internet) but also the quality of information and retrieval possibilities (by linking human-readable with machine-understandable information). The web could evolve into a global medical knowledgebase, where diverse medical Internet applications and resources are interconnected and integrated beyond manual linking, revolutionizing once again knowledge discovery and dissemination in medicine. Moreover, the Internet will (and partly has already begun to) revolutionize science itself by opening new ways of scholarly communication and electronic publishing.

APPENDIX - A
PROJECT GANTT CHART

STAGE # 1 – EMPA 301 COURSE

TEPS	10/13-10/19	10/20-10-26	10/27-11/2	11/3-11/9	11/10-11/16	11/17-11/23	11/24-11/30	12/1-12/7	12/8-12/14	12/15-12/20
Develop research question	■	■								
Identify Dependent & Independent Vari.			■							
Literature Research			■	■						
Operationalizing The Research					■					
Measuring Secondary Data						■				
Revision of Project Status							■			
Making adjustments								■		
Design Survey questions								■	■	
Analyze data for Final proposal									■	
Complete Final Proposal paper										■

STAGE #2- EMPA 396

PROJECT STAGES	1/10-1/16	1/17-1/23	1/24-1/30	1/31-2/6	2/7-2/13	2/14-2/20	2/21-2/27	2/28-3/6	3/7-3/13	3/14-3/18
Sampling	■									
Literature Research		■	■							
Making adjustments survey			■	■						
Data Collection (Phone Call Survey)					■	■	■			
Secondary Data Collection						■	■			
Analyze & Aggregating Data Collected							■	■		
Communicate challenges to Instructor									■	
Final Presentation Power Point & Final Capstone Paper										■

Appendix- B

Research Proposal Data Collection
Survey Form

This survey is to be completed by each patient over the telephone interview.

Data Collection Rules:

1. All the samples (patients) within the selected group are to be informed their patient rights thereby can refuse participating for this survey and to be informed the purpose / research proposal.
2. The data can only be collected from the selected group sample i.e., Current Kaiser -Oakland medical center health plan member who are identified as chronic diabetic patients:
3. Population 200 and, Sample # 100
4. Methods of survey: Phone call

	Survey Questions	Yes	No	No Comment
1	Are you a current Kaiser health plan member who is diagnosed with chronic diabetic?	100%	0%	0%
2	Do you have a computer or access to the internet?	60%	40%	0%
3	Do you know how to navigate the Internet and access your health information or make appointment with your provider online?	50%	45%	5%
4	Since Kaiser implemented the new electronic medical record system have you experienced improved quality of care or service?	70%	20%	10%
5	Do you believe your diagnosis can be managed effectively through e-Health just as a personal interaction with your physician?	60%	40%	0%
6	Do you believe your health information is safe and secured on e-Health (electronic medical record) system?	80%	15%	5%
7	As a Kaiser health plan member, do you believe the benefits of e-Health outweigh the potential risk involved for patient information privacy?	90%	5%	5%
8	Do you believe Kaiser has a secured and safe electronic medical record system to keep your health information private?	40%	50%	10%
9	Overall are you satisfied with the level of care provided since the implementation of e-Health?	85%	10%	5%

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