

THE IMPACT OF EHEALTH INFORMATION ON PATIENT
MEDICATION ADHERENCE, ATTITUDES AND KNOWLEDGE

by

MÉLANIE PROVOST

(Under the Direction of Matthew Perri III)

ABSTRACT

Non-adherence is a public health problem costing over \$100 billion/year. Patients' lack of belief in the medication benefits and lack of information about the drug are important determinants of medication adherence. The Internet may be a pathway to improving patient knowledge. Although 73 million Americans have used the Internet to seek health information, little is known about the consequences of this eHealth behavior.

Adapted scales assessing eHealth self-efficacy, perceived impact of using eHealth, and Personal eHealth Information Outcomes Expectations were tested within the theoretical framework of the Social Cognitive Theory. EHealth self-efficacy is defined as an individual's perception of his or her ability to use the Internet to find health resources. In a cross-sectional design, 132 adults completed a 43-item online survey. Higher levels of eHealth Self-efficacy are significantly associated with eHealth use ($r=0.21$, $p<0.05$), Web browsing self-efficacy ($r = 0.34$, $p<0.01$), Personal eHealth Information Outcomes Expectations ($r = 0.34$, $p<0.01$), Computer Anxiety ($r=-0.24$, $p<0.01$) and Perceived Impact of using the eHealth information ($r = 0.32$, $p<0.01$).

A randomized controlled trial evaluated the impact of eHealth information seeking on patient's medication adherence, knowledge, attitudes, and patient-provider relationships. The intervention consisted of eHealth Web sites linked in a Web portal. Eighty-one Internet users taking medications for diabetes, dyslipidemia, and/or hypertension participated in the 2-month

prospective study. No significant differences on the outcomes measures were noted between experimental groups. However, clinically significant changes in medication dosage, contacts with doctors, and increased awareness of potential side effects were observed among the eHealth information participants.

The third study identified opinions, preferences and types of behaviors regarding eHealth information use, for health professionals and patients in United States and Europe. In a cross-sectional design (n=2621 respondents, USA 38%; Europe 29%), health professionals preferred using medical search tools but patients preferred general search tools. 69% USA patients and 47% European patients have discussed their eHealth findings with their doctors.

Instruments with evidence of reliability and validity to assess constructs like eHealth self-efficacy should be useful to eHealth behavioral research. More research is needed to evaluate the impact of eHealth use on medication adherence and knowledge.

INDEX WORDS: Internet, eHealth, self-efficacy, scale development, medication adherence, compliance, knowledge, measurement, health information, reliability and validity, patient-provider relationships, patient education, United States, Europe, pharmacy, prescription drugs, hypertension, dyslipidemia, diabetes.

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DEDICATION

To my team of Provosts:

Magalie, Monique et Guy,

Avec tout mon amour.

In memoriam,

À la sortie du train, j'ai vu la ville;

et je l'ai trouvée belle.

Eugène Skorupski (1924-1999)

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CHAPTER 1

INTRODUCTION

Each day patients receive prescriptions from their physicians. Many factors influence whether they will take the medication or not, such as: doubts about the accuracy of the diagnosis, personal beliefs about taking medications, how much they know about the medication in question, its cost, or even fear of side effects. In fact, patients' lack of belief in the medication benefits and lack of information about the drug are two of the most important determinants of medication adherence [Fincham and Wertheimer, 1985]. Medication non-adherence, possibly as a result of low information levels on the part of patients, is a public health problem estimated to cost an excess of \$100 billion a year in United States.

In the current health care system, a patient will receive a prescription from the physician and have this filled at a pharmacy. During the doctor's visit, there is limited time to focus on medication information intended for the patient and his or her knowledge about diseases. At the pharmacy, counseling may be provided verbally, via written materials including leaflets, package inserts and flyers about specific drugs and medical conditions, or it may be omitted at the patient's request. While these channels of communication are important, a question arises as to the adequacy of this information since medication adherence is still low and the levels of information patients have is known as a key indicator of adherence.

The Internet may be an additional pathway to improving patient knowledge. The Internet is available to patients for self-education about diseases, medications and even health services, namely eHealth resources. EHealth includes use of the Internet or other electronic media by the public, health workers, others to access health related information, services, and support. [Eysenbach, 2001; Wyatt, Liu, 2002; Gustafson and Wyatt, 2004] Already 73 million adults in

the United States have looked on the Internet for health information (PEW Internet Project) [Horrigan, Rainie, 2002]. Further, pharmaceutical companies have used the Internet to provide additional information to patients about their products and the diseases these medications are used to treat. However, barriers exist for accessing online health information. On a societal perspective, not everyone within a same country or between geographical locations can currently use computers and access the Internet: this issue is known as the “digital gap”. In addition to the digital gap, there are issues related to readability levels of Web content, the large variety of information to select from, and the credibility of the information found online [Impicciatore et al., 1997; Jadad and Gagliardi, 1998; Pandolfini et al., 2000].

Patients have demonstrated a desire to take a greater role in their own care demanding more health information and more involvement in the medical decision making process. Health professionals, and especially pharmacists, can play a role in solving the problem of lack of patient knowledge by encouraging and facilitating self-education activities through the use of the Internet.

The objective of this study was to evaluate the impact of seeking eHealth information (drug or disease) or services on the Internet (‘eHealth Information Seeking Behavior’) on patient’s adherence, knowledge, and attitudes, and on patient-health professional relationship .

1.1 Specific Aims

This research addressed the question whether eHealth information seeking significantly influences medication adherence. The specific aim of this project was to determine the impact of 'eHealth Information Seeking Behavior' on: medication adherence, disease knowledge and patient-practitioner relationships. This main objective was investigated by examining outcomes of an experimental manipulation of eHealth information to a patient population.

A secondary objective is to assess the initial psychometric properties of adapted instruments and measures in eHealth studies, including the eHealth self-efficacy scale.

CHAPTER 2

BACKGROUND AND SIGNIFICANCE

This chapter will present an overview of four main topics integrated in this research project: eHealth, medication adherence, health information needs and theoretical background related to this research. Following an overview of the literature related to existing eHealth knowledge, gaps will be identified. Also, non-adherence to medication and gaps in health information received by patients in the health care system will be covered. A brief overview of the regulatory context will be presented to recognize the needs for health information over time based on safety and benefits for citizens. A theoretical framework for this research will be based on health behavior and communication theories reviewed in the subsequent section. Conclusive statements will include a short summary and the significance of the results of this research. The importance of this work will be presented within the health care context and the potential benefits of information system to provide supplemental health information to improve patients' quality of care.

2.1. Introduction

Patient health education is effective for improving health outcomes and is now required, for example, as part of the standard health care recommendation for diabetic patients [American Diabetes Associations, 2003]. Provision of health information is an integral part of health care. Information must accompany all prescription drugs and over-the-counter medications in the form of a proper labeling as regulated by the Food and Drug Administration (FDA). In addition, pharmacists must provide additional counseling to patients when dispensing a prescription drug

to conform to the Omnibus Budget Reconciliation Act of 1990 (OBRA '90 Act) and with the practice of pharmaceutical care [Hepler and Strand, 1990].

The provision of information by physicians and pharmacists is often limited due to a lack of time and financial compensation to offer the added care service. Inadequate information about prescribed drugs was cited as a contributing factor for non-adherence as long as 25 years ago [Lundin 1978; Turakka and Enlund 1978] and still remains a frequently cited factor explaining non-adherence [Fincham, Wertheimer, 1985; DiMatteo, 1994; Insull W, 1997; Larosa, Larosa, 2000; Vermeire et al., 2001]. Insufficient health information leads to non-adherence due to patients' reservations about following prescribed treatment.

The problem is observed at various levels based on the frequency of doses taken during the day. In fact, according to a review of 76 reports using electronic monitoring, the mean (SD) adherence rates for treatments in a variety of diseases are 79% (14) for once daily, 69%(15) for twice daily, 65%(16) for three times daily and 51%(20) for four times daily dosing ($p < 0.001$) [Claxton et al., 2001]. Therefore, simplicity of dosing can be seen as a solution to improve medication adherence.

Chronic treatments of asymptomatic illnesses and prevention treatments show a high rate of non-adherence. For example, about 50% of patients who received a prescription to treat hypertension stopped taking their medication 3 to 6 months after beginning the treatment [Jones et al., 1995; Cramer, Heart 2003]. Also, half of patients with dyslipidemia discontinued their treatment within 5 years [Avorn, 1998]. These observations lead to a conclusion of a greater need to evaluate intervention to improve adherence for people taking medication for chronic diseases.

Non-adherence leads to notable consequences not only for the individual but also on the societal level. Non-adherence carries costs in thousands of lives and a huge financial burden for the health care system [Department of Health and Human Services, 1990; Berg et al. 1993;

Donovan and Blake, 1992; National Pharmaceutical Council, 1992; Task force for Compliance, 1994]. For the individual, being non-adherent may lead to reduce health benefits from medications that are effective in reducing morbidity and mortality.

However, a positive aspect is that patients have become more involved in their health care and demand more information about their health conditions and drug treatments. Empowered with more information, they can take part in the decision-making process with their health care providers [Wallerstein, 1992; Funnell et al., 1991; Roberts 1999; Trevitt et al., 2001; Kim, Lehmann, 2003; Zablocki, 1998]. Patients with diverse illnesses (cancer, diabetes, HIV/AIDS, cardiovascular disease, rheumatoid arthritis) or undergoing invasive medical procedures gained health benefits from having an increased access to health information about their conditions [Bjornsdottir, 1999; Jimison et al., 1999; Jones et al., 1999; Mahler and Kulik, 1990; Cohen, 1988; Frierson and Lippman, 1987; Lorig et al., 1993]. On the other hand, the lack of information about diseases, disease screening, lifestyle recommendations (diet, smoking cessation, exercise), and about the proper use of medications significantly influences public health and societal costs of health cares.

The recent expansion of Internet technologies embraced by the general public has opened access to extensive, almost unlimited, amount and variety of health information that was previously restricted to health professionals. The Internet can be seen as a solution to resolve the information gap but can also carry concerns due to the potential for misinformation related to unreliable sources [Impicciatore et al., 1997; Bower 1996; Jadad, Gagliardi 1998; Pandolfini et al., 2000; Berland et al., 2001]. Also, several barriers exist to access relevant eHealth information and the access to the Internet itself remains a barrier for most people since users have been characterized as more educated and with higher incomes than non-users [U.S. Department of Commerce, 2002].

The integration of Internet health information in patient education by pharmacists and other health care professionals has a great potential. Every year, the number of Internet users has been increasing, and health-related usage has also been increasing. Internet users seek health information for themselves or on behalf of others. They can be characterized “direct” or “indirect” users (Fleisher, Bass, et al., 2002), respectively, or ePatients (Ferguson, Frydman, 2002). Epatients are using this channel to access health information, contact their health care professionals, obtain prescriptions, and to participate in a Web-based health intervention trials [Baker et al., 2003; Horrigan and Rainie, 2002; Fox and Rainie 2000; Tate et al., 2001; Tate et al., 2003; McKay et al., 2001; Clarke et al., 2002; Giménez-Pérez et al., 2002; Anderson et al., 2002]. Little is known on the impact of eHealth on patients.

To our knowledge, there is no empirical study to date done on the use and impact of eHealth information, including prescription drug information, available on thousands of Web sites, and used by more than 6 million Americans daily [Horrigan and Rainie, 2002]. Direct-to-Consumer Internet (DTCI) information for prescription drugs is currently provided by pharmaceutical companies but also by various governmental, non-profit or commercial groups as well as patients and individuals.

This study aims to determine if the provision of access to eHealth information (diseases, healthy behaviors, and prescription) has an impact on patients’ behaviors and attitudes, their relationship with health care providers, and ultimately their decision to comply with a prescribed drug regimen that can improve their health.

2.2. Health Information: Patient’s Needs and Regulatory Requirements

2.2.1 Patients / Consumers

The general public has been increasingly demanding health information. In the past decades, patients showed a desire to receive more information about their diseases and

treatments than patients of previous generations [Donovan and Blake, 1992]. Consumers can be empowered with further health information [Wallerstein, 1992; Funnell et al., 1991; Roberts 1999; Trevitt et al., 2001; Kim, Lehmann, 2003; Zablocki, 1998] but not all patients are the same in regard to their need for information and involvement in medical decisions [Nease, Brooks, 1995; Blackhall et al., 1995]. Today's consumers of health care are more involved and take part in the decision-making process.: patients are willing to question the physician's diagnosis, to ask for specific drug treatment, to seek a second opinion, or even to change doctors if the latter does not agree with them [Kasteler et al., 1976; CBS 1984; Basara 1994; Donovan 1995]. People seek online information related to their illnesses; treatments; healthy lifestyles; herbal/alternative therapy; clinical trials; health insurance; clinicians; support groups, or to purchase drugs [Baker et al., 2003; Murray et al., 2003; Taylor and Leitman, 2003; Provost et al., 2003; Horrigan and Rainie, 2002; U.S. Department of Commerce, 2002]. Consumers also fear control by payors and health management plans wanting to save on costs by not providing them with the best treatment options. Consumers seek health information in various sources to verify drug selection by the doctors or simply to learn more about their health.

Sources of information available to consumers include direct contacts with health professionals, friends and relatives, direct-to-consumer advertising of prescription drugs, health-related broadcast news, television programs, magazine and newspaper articles, and the extensive amount of eHealth information that can be found on the Internet. The printed and broadcast press is also responding to the demand by presenting more health¹ news as well as television programs on health subjects. There is also an expanded selection of books, often bestsellers, covering health-related topics.

Consumers feel empowered with more information regarding their own health or health of their loved ones [Eng et al., 1999; Gustafson et al., 1999; Silberg, 1998]. Being partners in

¹ For example, <http://www.cnn.com/HEALTH/> [Accessed July 9, 2004]

their health care teams can give them a sense of control over their disease. This partnership can help them achieve better health behaviors that include self-monitoring of adverse drug reactions and drug effectiveness, adhering to the doctor's prescribed regimen, and learning about lifestyle changes that can contribute to improved health.

Direct-to-Consumer Advertising

Direct-to-consumer advertising has stimulated a lot of research on health consumer behaviors in the past two decades. Several behaviors and characteristics of DTCA would also apply to eHealth seeking. Therefore, this section will present an overview of key components that brings knowledge on health consumers' behaviors that may help understanding eHealth seeking behaviors and its consequences.

Advertising, as a source of information, influences behaviors of patients asking for specific product in the doctor's office [Lipsky, Taylor, 1997]. Little is known about online advertising of prescription drug, also a form of eHealth information. Physicians have complained patients pressure them to prescribe inappropriate treatments or trigger lengthy discussions related to the advertised drugs [Lipsky, Taylor, 1997]. Similar concerns exist with patients bringing information printed from the Web in the doctor's office [Ferguson, 2002].

Consumers have a favorable attitude toward receiving information via advertising of prescription drugs [Perri, Nelson, 1987; Perri, Dickson 1987; Williams, Hensel, 1995; Perri, Dickson 1988; Scott-Levin Associates, 1990]. Although of commercial intent, ads allow consumers to learn about both benefits and risks of medications [Schommer et al., 1998]. The intrinsic objective of advertising carries a legitimate caveat due to the potential marketing biases in the information provided to consumers. The effectiveness of advertisements to provide balanced information is questioned [Perri, Shinde, Banavali, 1999; Morris, 1984]. The information provided through DTC ads about benefits and risks of prescription drugs are not

clear to the consumers and raises serious questions [Schommer et al., 1998; Perri, Shinde, Banavali, 1999; *Prevention* Study, 1998].

The majority of consumers seek more information about a drug as a result of seeing a prescription drug advertisement [Perri and Dickson, 1987; Morris et al., 1986], and since each advertisement must provide consumers with additional references for further information such as a Web site or 1-800 number [FDA Guidance, 1999], consumers are using the Internet to access supplemental drug information. This type of eHealth information provided by the drug manufacturer can be entitled: “direct-to-consumer Internet information (DTCII)”. With more than \$2.5 billion spent yearly for advertising directly to consumers, there is an increase in awareness of DTCII that can be a significant source of eHealth information for the public. However, based on a nationally representative survey conducted by the *Prevention Magazine*, 13% of individuals who have seen an ad sought further information on the Internet. This seems a low percentage, but it should be interpreted in perspective that only 5%, and 9% seek information in magazines or used the toll-free telephone numbers respectively [Slaughter, 2002].

2.2.2. Regulations

Over the years, numerous regulatory measures were taken to provide more information in order to assure public safety. Consumers receive more information to improve their knowledge and awareness about prescription drugs. Almost a century ago, in 1906, the Pure Food and Drugs Act addressed labeling as the first US federal legislation governing food and medications [Palumbo, 2002]. It was only in 1968 that the U.S. Food and Drug Administration (FDA) required a patient package insert (PPI) for isoproterenol inhalation products, then followed in the 1970s with required PPIs for birth control pills and some other drugs. Only in 1979 did the FDA propose regulations requiring PPIs for all prescription drugs. The FDA requires adequate drug labeling that includes the mention of risks (cautions and warning

statements) and approved indications. Therefore, it has been more than 20 years that US citizens have received information about their prescriptions if they receive and read a PPI. The FDA Patient Package Inserts (PPIs), now renamed “Medication Guides”, were required in June 1999 [Smith 1999].

Recently, the FDA decided on the implementation of mandatory patient information to accompany 95% of all prescription drugs by the year 2006 [Dickinson, 1995; Federal Register, 1995]. These will be regulated and necessary provision of information when a drug is given to a patient; however, still little information would be provided about the disease itself.

Package inserts of prescription drugs are often not intended to be motivating for the patient to read it except in some cases if in combination with direct-to-consumer advertising [Smith 1999]. The leaflets are often not adapted for the intended audience presenting too much information written in a small font. Information leaflets may not be read by patients even when they are enrolled in a study [Graham, 2000, BMJ; Anon. 2001 Community Pharm; Anon. 2003 Community Pharm]. Less than 60% of patients reported fully reading the information leaflet in a randomized controlled trial [Graham, 2000]. However, as the FDA Medication Guide requirements are fulfilled, standardization of the format may lead to an improvement in the proportion of patients reading the information.

The increasing demand for more drug information also led to another form of information in the 1980s. The first US prescription drug advertisement by Boots Pharmaceuticals product called Rufen® (ibuprofen) [Palumbo, Mullins, 2002; Pines 1999]. In order to study the situation, the FDA asked the pharmaceutical industry for voluntary moratorium on direct-to-consumer advertising (DTCA) until 1982. In 1997, the release of the FDA’s draft guidance on DTC broadcast advertisements allowed advertising. Following the 1999 FDA Guidance, pharmaceutical companies have been increasingly spending for DTCA of prescription drugs to raise awareness on the availability of treatments and “educate” (a word that is controversial due

to the commercial purpose) the public about the disease to seek treatment and increase communication with the physician. The American College of Physicians (ACP) has conveyed its support for increasing consumer healthcare awareness but questioned if the accuracy of information in advertisements and whether advertising is the best way of distributing health information [American College of Physicians, 1998 position paper]. The American Medical Association disapproved advertising of prescription drug unless the advertisements are disease-specific for enhancing consumers' education with a clear and accurate health education message; the advertisements must be fairly balanced and clearly explain warnings and potential adverse drug reactions to encourage communication between patients and physicians. Also, the advertisement should be part of a manufacturer's education program for both patients and physicians [AMA, Policy H-105.988; AMA 2000; Palumbo, Mullins, 2002].

One of the supportive arguments for DTC advertising by all groups, including consumers, has been to bring healthcare information to consumers – more precisely, prescription drug information. As the Internet become more equitably accessible, this channel of communication by the pharmaceutical companies can become a preferable option to educate both consumers and physicians in a more comprehensive and balanced, up-to-date and rapidly accessible manner.

The primary source of health information for consumers remains their physician, as shown in a study of patients visiting an oncology clinic [Peterson, Fretz, 2003]. For information more specific to their prescribed drugs, the pharmacist is a specialist easily accessible at almost any time to answer questions through the phone or meet with the patients without charge for additional counseling. The practice of pharmacy has shifted from a product-oriented distribution to a more comprehensive disease management approach through pharmaceutical care services. With the OBRA 90 Act, pharmacists are required to provide pharmaceutical counseling when dispensing a prescription drug. Due to time constraints, little information may

be provided but can be supplemented with a printed information page about the product. The supplemental information about the disease and some disease-related information, if any, are often provided verbally or with education documents provided by pharmaceutical companies. Consumers are also in a rush, may not want to discuss personal health information in front of the other customers waiting nearby, and may sign to refuse counseling. Although a part of pharmaceutical care, patient education about the drug and disease, as well as lifestyle changes recommended within treatment guidelines [American Diabetes Association, 2003; National Heart, Lung, and Blood Institute, 2003], are currently lacking. For example, the American Diabetes Association considers education as a necessary element of standard medical care for all diabetics; even though more than 17 million Americans are living with diabetes and the prevalence will escalate in the next decade [American Diabetes Association, 2003(2); CDC 2002]. Pharmacists as well as physicians can not fill this gap of information for all citizens who need it, nonetheless pharmacists can encourage self-education by consumers who could access education tools publicly available free of charge on the Internet. However, health care professionals need to know more about the impact of recommending Web sites on their patients, and also determining which Web sites are reliable and helpful to the patient's health benefits.

Another aspect of regulations relative to drug information provided to consumers relates to the historically common-law doctrine called learned intermediary rule (LIR) which requires manufacturers to provide risk information to physicians who are the gatekeeper for prescription therapy because they have been perceived as best situated to convey meaningful information about risks and benefits to patients and because pharmaceutical manufacturers lack effective means to communicate directly with patients [Mello et al., 2003]. Recently, the New Jersey Supreme Court concluded that none of these reasons applies when a drug is advertised directly to consumers (Perez vs Wyeth Laboratories Inc.) [Perez v Wyeth]. If laws require more

communication between the manufacturer and the consumer, the Internet can be a medium to connect these important players of the health care system.

In summary, the demand for information by consumers who want to take part in their health care decisions as well as regulatory constraints, requirements and current reflections, are meaningful reasons for evaluating the potential of the Internet for structured provision of health education about prescription drugs and its impact on patient's behaviors, attitude, and potential health benefits.

2.2.3 Provision of Health Information by Healthcare Professionals

An active, co-operative relationship between patients and doctors is a key factor to improving rates of adherence [Donovan and Blake, 1992]. This relationship is only possible if health professionals recognize patients' abilities to make decisions, try to understand patients' needs and constraints, and work in partnership with patients in treatment choices [Donovan and Blake, 1992]. Understanding patients' needs for health information, most professionals would wish to contribute to public health education. Due to the workload related to drug dispensing and the shortage of pharmacists, it is difficult for pharmacists to invest in developing and offering new health education services. In many settings, physicians are also in the same situation where their time is precious and limited to essential medical services.

Health care professionals provide most health information verbally to patients. This can lead to a reduced usefulness of the information since verbal provision of information by the pharmacist and physician is likely to be forgotten. Further, the workload at the pharmacy may limit patient education about diseases. When patients are at home, they are left with the decision to start or continue taking the medication as prescribed. Without sufficient information, medication adherence will not be at optimal levels. The health care system presents some barriers to the implementation of educational programs that can contribute to improve patients' adherence to treatment.

2.3. eHealth Information

2.3.1. Utilization of the Internet and demographics of Users

About one half of the population in United States has Internet access [U.S. Department of Commerce 2002]. Among them, 40 to 80% (55 to 110 million) have used the Internet for health-related purposes [Baker et al., 2003; Fox and Rainie, 2000; Horrigan and Rainie, 2002; Taylor H, Leitman, 2002a and 2003]. Up to 6.5 million US citizens access the Internet on a daily basis, to seek health information [Horrigan and Rainie, 2002], which is a larger than the number of people visiting a doctor in one day. Historically, the demographics of Internet users have been mainly more educated, male, of younger age and higher income [U.S. Department of Commerce, 2002]. As computer technology became cheaper and more accessible to almost anyone, the adoption of Internet use has been increasing and the demographics become more representative of the U.S. population [U.S. Department of Commerce, 2002].

As the number of Internet users increased, so did the proportion of people using it for health purposes. Accessing the Internet for health information seeking seems restricted to a certain population being more educated, younger, female and with higher incomes. The definition of eHealth includes use of the Internet or other electronic media by the public, health workers, others to access health related information, services, and support [Eysenbach, 2001; Wyatt, Liu, 2002; Gustafson and Wyatt, 2004]. Seventeen percent (17%) health Internet users reported looking for information often while 37% performed this activity sometimes [Taylor H, Leitman, 2003]. People use the Internet to seek health information for themselves but also almost half of them reported searching for someone else [Taylor H, Leitman, 2002b], which increases the previous proportions of US adults who can be influenced by health information found online.

Health consumers use the Internet to access health information about their illness and to access medical literature [Boyer et al., 2002], to learn more about a prescription drug [Baker et

al., 2003], to purchase medical device or medications [Baker et al., 2003], and also use email to solicit medical advice [Widman and Tong, 1997] or communicate with their health providers [Baker et al., 2003] or other individuals afflicted with the same disease [Weis et al., 2003]. Among adults who a received a prescription drug and had Internet access, 33% are estimated to have used the Internet or email to learn more about a prescription drug [Baker et al., 2003]. Although several pharmacy chains and health plans in the United States provide their customers with an Internet portal of health information, to our knowledge there is no report of the proportion of pharmacists who recommend specific Web sources of information, and if they do, how does it benefit their clientele.

Among a group of patients afflicted with a cancer, their most common source of information about their disease was their referring physician (47%) or the sub-specialist physician (82%), while the Internet was the third most common source (16%) [Peterson, Fretz, 2003]. The Internet is also a channel of communication connecting individuals affected with rare or prevalent diseases. They can gather, seek, or provide information online to other people afflicted by the same disease, or share experiences between themselves [Weis et al., 2003].

Most people use general search engines when they seek health information online [Taylor, Leitman, 2003; Boyer et al., 2002]. More experienced users may go directly to their favorite health-related Web sites or follow their relatives', family members' or health professionals' suggestions. Some people are invited to visit commercial Web sites through advertising on the Web, television or other media. This type of invitation is actually one aspect of the FDA's guidelines to encourage the provision of supplemental information in direct-to-consumer advertising of prescribed medication.

Although increasingly popular, the Internet is not currently being used at its optimal potential as a source of health information. Health care professionals are concerned about the reliability of information [Eng et al., 1998; Coiera 1998; Silberg, Lundberg 1997; Sonnenberg

1997; Wyatt 1997; Impicciatore et al., 1997], or have simply not incorporated it into their daily practice. Some physicians began recommending Web sites when patients requested their suggestions or talked about the Internet. It is unknown to which extent these recommendations are followed or how it affects patients' behavior or satisfaction with care received. Most people would expect benefits from giving access to reliable and relevant information and disease management programs on the Internet. However, not every patient is provided with the equal access to this source of health information.

One simple solution for increasing Internet access has been suggested: increase the number of Internet terminals available in community settings [Kalichman et al., p.526, AIDS Care 2002]. Community technology access centres (CTAC) were encouraged by the White House (2000) to bridge the digital divide and provide access to all Americans [White House, 2000]. Other initiatives target disease-specific community, for example people living with HIV/AIDS [Kalishman et al., Aids Care 2002].

2.3.2. Health Information on the Internet (eHealth information)

Content

There are between 20,000 to 50,000 Web sites related to health that can be accessed on the Web [Miller et al., 2000; Cozens 2001; Byrne 2001; Manhattan Research 2002]. A simple search using Google.com search engine with the key word 'health' retrieved more than 100 million Web pages [Searched on August 3, 2003] and reached about 232 million pages about a year later [Searched on July 9, 2004]. If users want to seek more specific information, for example on 'diabetes' or 'cancer' there are more than 6 million and 17 million Web pages, respectively [Searched on August 3rd, 2003]. The numbers of retrieved pages in both of these conditions also doubled a year later [Searched on July 9, 2004].

Information more specific about drug therapy can be reached using a keyword search or within categories on a health Web sites. Using the search engine with a medication name can make it difficult to discern relevant resources since several commercial sites selling prescription drugs are retrieved and do not even provide information. It is of concern that these sites may not be legal e-pharmacies and the country in which they are located cannot be determined.

United States governmental agencies such as the National Library of Medicine¹ offers a database on medications aimed at the general public that was developed in collaboration with the American Society of Health-System Pharmacists (ASHP) through MedMasterTM, and through the USP DI® Advice for the Patient®, a product of the United States Pharmacopeia (USP). The FDA² makes available other types of information about drugs such as warning letters or safety warnings as well as a searchable database of approved drugs. Several commercial Web sites use databases of information provided by the Thompson's Desk reference. Pharmaceutical manufacturers also provide Web sites for most of the newly marketed products or at least provide a patient package insert on the company's Web site.

In general, a Web page presenting information about a drug is product specific (purpose, side effects, warnings, dosage, drug and food interactions) but, sometimes, links to disease-related information are provided on the page or if the visitor navigates through the Web site.

Credibility and Quality Concerns

Valid information on the World Wide Web is difficult to access due to the rapid growth and uncontrollable manner that health information has been accumulating on the Internet [Jadad, Gagliardi 1998]. The quality of health related Web sites has been of concern for researchers and health professionals due to uncontrollable amount and variety of content now

¹ URL: <http://www.nlm.nih.gov/medlineplus/druginformation.html> [Accessed July 9, 2004]

² U.S. FDA Center for Drug Evaluation and Research, URL: <http://www.fda.gov/cder/> [Accessed July 9, 2004]

available online to consumers. It is unclear whether the poor quality of health information is a public health problem or not [Coiera, 1998].

In the name of free speech, it is unlikely that the Web health information needs to be, or will be, regulated. However, several organizations in several countries and government agencies are evaluating or are developing mechanisms to accredit health Web sites. In the United States, the URAC (American Accreditation HealthCare Commission formerly Utilization Review Accreditation Commission)¹ accredits health Web sites paying a subscription fee, and the American Medical Association (AMA) developed guidelines [Winker 2000], while in Europe, a European Union commission recently published their criteria [eEurope 2002]. Also, more than 3000 Web sites currently abide by the Health On the Net (HON) Foundation's² Code of Conduct [HON, 1997]. The Internet is a global entity and will probably always be so. Should the Internet quality evaluation be global? Harmonization of Internet based health information evaluative efforts would benefit all users and international researchers. Some have challenged the notion of regulating or imposing quality standards for the Internet because the Internet should not be more regulated than other mediums for exchanging information [Anon. 2002; Ferguson 2002; Purcell 2002]. Nonetheless, consumers can be empowered with more health information [Wallerstein, 1992; Funnell et al., 1991; Roberts 1999; Trevitt et al., 2001; Kim, Lehmann, 2003; Zablocki, 1998]. Some feel consumers can take care of themselves when advised by community watchdogs [Charatan 2002].

The quality of health information remains a concern and a public health issue. However, the "epidemiology" (distribution and determinant) of the problem remains unclear [Eysenbach G, Powell J, Kuss, 2002; Coeira, 1998]. More than 79 studies evaluated health Web sites against

¹ URAC, American Accreditation HealthCare Commission, Washington, DC, USA, URL: <http://www.urac.org> [Accessed July 9, 2004]

² . Health On the Net Foundation (HON), Geneva, Switzerland, URL: <http://www.hon.ch> [Accessed July 9, 2004].

specific criteria [Eysenbach G, Powell J, Kuss, 2002]. Seventy percent of the studies (55) concluded that quality is a problem while 22% had a neutral conclusion and 9% came to a positive result regarding the quality of health Web sites [Eysenbach G, Powell J, Kuss, 2002]. However, the impact on public health should be placed into perspective. Wide variability in quality of health information in other media also exists and the risk encountered by consumers depends on their ability to filter the adequate information [Eysenbach G, Powell J, Kuss, 2002].

2.3.3. Potential Benefits and Risks of the use of the Internet for health purposes

The considerable amount of health information and resources available on the Internet has great potential to improve health [Robinson et al, 1998; Eng et al., 1998] but concerns exist relative to the inaccuracy of information [Eng et al., 1998; Coiera 1998; Silberg, Lundberg 1997; Sonnenberg 1997; Wyatt 1997; Impicciatore et al., 1997] or dangerous and unsafe content that can lead to harmful health consequences [Micke 1996; Weisbord et al., 1997] or even death [Athanaselis et al., 2002].

The use of the information found online may be seen as promoting the communication with health care providers, increasing public health knowledge and raising awareness of consumers to seek medical treatment, but can also be seen as a threat to the patient-physician relationship.

Benefits

Computer-based health information systems used by people living with HIV/AIDS have shown positive outcomes including improved health and reductions in hospitalizations [Brennan and Ripich, 1994; Gustafson et al., 1999; in Kalishman et al., 2002]. Patients with cardiac heart failure using home telemonitoring devices had a reduction in health care costs and hospitalizations. The telemonitoring device provided interactive tailored information-based

intervention and collected health measures. This system allowed categorization of patients by health status that helped health care professionals to target interventions to patients who needed monitoring [Guendelman et al., 2002; O'Connell and Cherry, 2000; Johnston et al., 2000]. This device, called HealthBuddy®, was also used in a self-management and educational asthma program tested in a randomized controlled trial with inner-city children and demonstrated that the children using the technology-based educational program were more likely to improve self-care behaviors including taking asthma medication without reminders, and to reduce asthma symptoms, while making fewer urgent calls to the hospital, after adjustments for baseline covariates and time [Guendelman et al., 2002]

Risks

At the moment, the potential negative impact of misinformation or bad health Web sites on users' health is unknown. There is only isolated evidence of harmful effects by the use of information found on the Web [Athanaselis 2002; Smith 2001; Kiley 2002; Crocco 2002].

There is at least one online monitoring initiative that exists¹ [Eysenbach and Kohler, 2002]. The Food and Drug Administration (FDA) also scrutinizes false claims on the Web, and takes actions through warning letters sent to faulty Web sites making false claims on products they advertise for sale. There is limits to the scope of the monitoring due to the extensive content of the Internet. Tatsioni et al. found that there is a potential risk related especially to safety information on drugs with major FDA safety warnings; the majority (two thirds) of Web pages evaluated inadequately covered the important safety warnings even in sites provided by pharmaceutical companies, government, medical associations and universities [Tatsioni et al., 2003]. However, the methodology employed in that study to retrieve Web pages may not be

¹ Eysenbach G, Köhler C. DAERI Database Adverse Events Related to the Internet, Heidelberg, Germany, URL: <http://www.medcertain.org/daeri/> [Accessed July 9, 2004].

representative of how the public would search and select Web pages. It is unknown if the users would actually retrieve accurate or inaccurate information.

Nevertheless, toxicity information is important for people using a drug that has been issued a safety warning since misinformation can lead to severe adverse reactions that can even threatened the patient's life. Informed patients can become aware of toxicity signs, contact their physicians and stop taking medications to prevent worsening of adverse drug reactions detected early. On the other hand, patients misled with inadequate warnings online may fail to recognize toxicity and continue taking drugs that have been withdrawn [Tatsioni et al., 2003]; however, pharmacists and physicians will also likely make an effort to communicate with patients taking these medication when a warning is issued.

The content or communications with an unknown person can also carry some risks. Unqualified people can give wrong advice on the Internet. People can also find online instructions on how to commit suicide or potentially harm someone. An inability to filter the inadequate web sites can increase the risk of harmful use of wrong health information [Eysenbach, Powell et al., 2002]. Also, another type of risk relates to the use of self-treatment recommended or purchased online that, in some cases, can delay seeking medical advice from a physician.

2.3.4. Kiosk Interface and Public Access

Stand-alone computerized interfaces, known as kiosks, used to provide health information in public places, are older than the World Wide Web boom. As it is already seen in United Kingdom, there are chances to see more and more Web-enabled kiosks in public places, which will increase eHealth information access. In this perspective, this section presents a review of kiosk as a type of access to eHealth information.

The first prototype kiosk used for health purpose, was developed in 1988-89 (United Kingdom), provided information on drugs, contraception, AIDS, and other topics, as well as lists of local health services sites and support groups [Jones, McLachlan and Bell, 1990]. A touchscreen version followed in 1991 [Jones, Naven, Murray, 1993]. The adoption of kiosk technology combined with the Internet connectivity is growing in interest worldwide.

Research projects about the use and implementation of touchscreen kiosks to provide health information are being done in several locations including Michigan [Connell, 2003], Columbus, Ohio [Westman, 2000], Eugene, Oregon [Glasgow, 2002], in London [Nicholas, 2001] and through out the United Kingdom [Nicholas, 2003a-b], as well as several countries of Europe (Northern Ireland, Germany, Portugal and Italy) regrouped in a consortium project [Moore, 2001]. Several health subjects are presented to the public (Table 2.1), but to our knowledge, none focused on providing information about prescribed medication in pharmacy settings.

Table 2.1 Touchscreen Kiosk Studies

Location	Number of kiosks (duration)	Health Content
Clydebank, UK [Jones, Navin, Murray, 1993]	10 (5 months) (sample from 25 kiosks in various places, including a chemist, health center, library and a pub)	Smoking, AIDS, Alcohol, Women's health and Sex were the most access topics.
Michigan, USA [Connell, 2003]	100 (since 1996)	Smoking cessation and prevention, childhood immunization, breast cancer, prostate cancer, Alzheimer disease, child bicycle helmet safety, cancer prevention, cardiovascular disease prevention, nutrition and exercise
Columbus, Ohio, USA [Westman, 2000]	1 kiosk (7 months), 2 kiosks (4 months)	Cancer risk assessment and surveillance recommendations.
6 small to moderate size communities within 30 miles of Eugene, Oregon, USA [Glasgow, 2002]	1 touchscreen computer (3 session per subjects, 60-120 min. per session, at baseline, 3 and 6 month visits.	Dietary goal-setting intervention for type II diabetes.
London, UK [Nicholas, 2001]	2 (2h, once or twice a day, for 12 weeks)	Medical conditions, surgical operations, health news, healthy living, and health directory, A-Z to the National Health Service (NHS), travel clinic
United Kingdom [Nicholas, 2003a]	(9 months) (sampled from the 200 kiosks in the UK)	Medical conditions, surgical operations, health news, healthy living, and health directory, A-Z to the National Health Service (NHS), travel clinic
United Kingdom [Nicholas, 2003b]	20 (3.5 years) (sample from > 50 kiosks under study in the UK)	Medical conditions, surgical operations, Health news, healthy living, support groups, Health directory, A-Z to the National Health Service (NHS), and travel clinic
European Consortium (Northern Ireland, Germany, Portugal and Italy) [Moore, 2001].	N/A	Cardiology, and Skin cancer

The Michigan Interactive Health Kiosk Project, launched in 1996, provides access to several health subjects via 100 touchscreen kiosks [Connell, 2003]. They are located throughout the state in public places including public libraries, churches, senior centers, schools, fast-food restaurants, shopping malls, grocery stores and hospitals. Users can access with the press of their finger, information on smoking cessation and prevention, childhood immunization, breast cancer, prostate cancer, Alzheimer disease, child bicycle helmet safety, cancer prevention, cardiovascular disease prevention, nutrition and exercise [Connell, 2003]. Their usage data confirms that the highest level of usage is reported among teens and young adults, the average age being 32 years but an extensive use is seen among middle aged and older adult population [Connell, 2003]. Users of kiosks are more likely to have experience with personal computers and Internet than non-users of kiosks [Strecher, 1998]. Older people may have the perception that computer expertise is required to use the technology, and since they have less experience with personal computers [Czaja and Sharit, 1998], this may explain their hesitation to use the kiosk [Connell, 2003].

There is a gap in knowledge of the impact of the use of eHealth information available via the kiosks in the previous published studies. In a small sample (n=59, 29% response rate), almost all respondents felt “very comfortable” using the risk assessment cancer kiosk [Westman, 2000]. Twenty percent of respondents reported to have made changes in their own or their family’s cancer surveillance practices [Westman, 2000].

No comparative study on the use of a single Web site accessed using a computer or a kiosk has been done. Nicholas et al. (2003a) compared the metrics and numbers of the two platforms (publicly accessible health Web site SurgeryDoor¹ and a touch screen health information kiosk also from InTouch With Health²). One of their observations revealed that time

¹ <http://www.surgerydoor.co.uk>, studied in July and November 2000. [Accessed July 9, 2004]

² 50 kiosks studied from January to September 2000.

taken to view a kiosk page (11 seconds) is less than the time to view a Web page (69 seconds) [Nicholas, 2003a].

2.3.5. Summary related to this research

Before health professionals can recommend specific Web sites to the public for supplemental information, there is a need to assess the impact of eHealth use on patients. Mass advertising, including DTCA of prescription medication, encourages access to these Web sites and provides us with a second underlying reason for studying the impact of prescription drug-related information accessed via the Internet. One third of people with Internet access and who had a prescription in the previous year reported that they had used the Internet or email to learn more about a prescription drug [Baker et al., 2003]. There are limited evidences about the impact of drug information seeking by patients receiving a new prescription for chronic illnesses. To our knowledge, no prospective study has been done to evaluate the impact of eHealth information use on medication adherence.

2.4. Medication Adherence

2.4.1. Overview

More than 30 years have passed since the first workshop on adherence research [Sackett 1975; Vermeire et al., 2001], but many centuries ago Hippocrates was aware that patients pretended to have taken their medication [Sackett 1979; Vermeire et al., 2001]. Most studies published between 1975 and 1999 took the term “compliance” for granted [Vermeire et al., 2001]. Although many authors do not even consider defining it [Donovan 1995; Vermeire et al., 2001], “Compliance” can be seen as a word with negative connotation suggesting complaisance and submission [Vermeire et al., 2001]. It has been defined as “attempting to take the medication each day as prescribed [Claxton, Cramer and Pierce, 2001]. “Concordance” is the term selected by the Royal Pharmaceutical Society for its meaning of agreement and

harmony [Vermeire et al., 2001]. Concordance involves the patient as a decision maker (Royal Pharmaceutical Society) [Vermeire et al., 2001] underpinned with professional empathy [Miborn, Cochrane, 1997]. A growing number of professionals propose the term “adherence”. The term “compliance” brings a notion of greater power to the doctor in the doctor-physician relationship while the term “adherence” reduces this attribution of greater power to the doctor.

Vermeire et al. (2001) wrote: “if people are to be involved as equal partners in decisions concerning their health care, then doctors will have to adjust their role from being the sole decision maker to being expert-advisers.” Adherence is a word of “co-operative behavior” [Holm 1993; Vermeire et al., 2001]. In concordance with the type of intervention that necessitate an active role by the patient seeking eHealth information, the term “adherence” will be used in this project. The “persistence” will also be considered within certain limits due to the short duration of the study. Persistence is defined as “continuing to take the medication long term” [Claxton, Cramer and Pierce, 2001]. Non-persistence may occur when patients feel they no longer need medication and discontinue treatment without medical recommendation [Cramer, 2003].

Effective medications exist to prevent morbid or life-threatening consequences of diseases. In most cases, drugs need to be taken chronically to bring long-term benefits or increase life expectancy. The concept of *evidence-based medicine* encourages health professionals and decision makers to rely on clinical trials for demonstrated effectiveness or benefits. However, the “real life” circumstances and patients, as compared to clinical trials, often differ. About 75% of medication is taken as prescribed in a variety of medical disorders [Cramer, 1989; Cramer 2003]. Others are even more pessimistic and conclude that health professionals should expect poor adherence in 30-50% of all patients, irrespective of disease, prognosis or setting [Morris, Schulz, 1992; Sackett, Snow, 1979; Lassen, 1998; Donovan, 1995; Griffith, 1990; Vermeire et al., 2001]. Medication non-adherence is considered a major public health problem in addition to the financial burden estimated to be about \$100 billion per year in

health care and productivity costs [Department of Health and Human Services, 1990; National Pharmaceutical Council, 1994]. This social problem contributes to 10% of hospital admissions and 23% of admissions to nursing home [Morris, Schulz 1992; Donovan 1995; Vermeire et al., 2001]. Poor adherence with therapeutic regimen is related to clinical outcomes [Melnikow, Kiefe 1994; Vermeire et al., 2001] and increased risk of death [Sheperd, 1997]

Patients can be optimal compliers, or intentionally or unintentionally inadequate compliers [Rudd 1994; Cramer, 2003; Donovan 1995; Donovan and Blake, 1992; Conrad 1985]. Inadequate adherence can relate to an occasional missed dose, an occasional extra dose, erratic dosing, or a consistent pattern but not as prescribed [Cramer, 2003]. Partially compliant patients may not plan well to take their medication, may be forgetful, have altered daily schedule, be confused about instructions, face a lack of efficacy or adverse drug reactions, or be consigned to financial difficulty to afford the cost of the treatment [Cramer, 2003]. Intelligent non-adherence is a different issue when patients decide apparently rationally that they do not need as much prescribed medication [Cramer 2003], or related to a misdiagnosis, inappropriate prescribing, the patient experiences adverse reactions, or the patient with a chronic condition become aware that the disease has changed [Britten 1994; Vermeire, 2001]. Different interventions can be implemented depending on the patient's non-adherence profile.

Although more than 200 variables have been studied since 1975, none of them and including socio-economic and pathology-related factors can be considered as consistently predicting adherence [Vermeire 2001]. Although some associations have been found with demographic variables (age, sex, marital status, number of people in the household, social class) and disease factors, they are poor indicators of adherence. The directions of these associations were inconsistent between studies [Vermeire, 2001]. Another author reviewed the literature and concluded otherwise (see table 2.2, from Cramer 2003). It is neither related to psychological profiles including intelligence or memory [Cramer, 2003].

As confirmed in a review of studies using electronic monitoring systems [Claxon, Cramer, Pierce, 2001], adherence is inversely related to the number of doses per day the patient needs to take. Once daily dosing showed the highest adherence rate of 79% while twice daily dosing (69%), three times daily dosing (65%), and four times daily (51%) have smaller adherence rate. Side effects of a treatment can have an impact on adherence to that treatment [Vermeire, 2001]. Patients may also decide to reduce their drug intake in order to diminish the risks of side effects [Donovan et al., 1989].

Table 2.2 Factors Associated with Medication Adherence

Factors that correlate with adherence	Factors that do not correlate with adherence
Dosing regimen (frequency)	Gender
Patient lifestyle	Educational level
Use of other medications	Socio-economic status
Side effects (to some extent)	Disease state
	Disease severity

Reproduced from Cramer et al., Medicine Partnership. Heart 2003; 89(suppl II):ii19-21.

The measurement of adherence to prescription drug can be performed directly or indirectly. A direct measure is not available for some medication since it involves the detection of a chemical (metabolite or marker) in a body fluid (blood or urine). Chemical analyses are considered the most accurate although usually invasive and costly [Vermeire, 2001]. Indirect measures, more commonly used, include process measures such as interviews, diaries, tablet counts, prescription filling dates and therapeutic and preventive outcome measures [Vermeire, 2001; Gordis L., 1979]. The use of microprocessor technology, or medication event monitoring systems (MEMS), provides more accurate measures enabling frequency and time of opening of the medication bottle [Vander 1991; Raynor 1992; Vermeire, 2001]. Some evidence supports the idea that the electronic medication dispensers may enhance adherence [Raynor 1992; Vermeire, 2001]. A minimum of two indicators is recommended when assessing adherence [Stewart RB, 1989; Spilker 1991].

Although the problem of non-adherence is complex, the solution must provide simplicity for the patients. Proposed solutions include short-term regimens, fewer doses per day, lower medication costs, easy-to-use packaging, reminders, tailoring, patient education, and patient satisfaction measurement [Vermeire, 2001]. Clinical pharmacy services (medication histories and review, optimization of therapy to achieve desired outcomes, and reduction in adverse medication events) are beneficial to enhance medication adherence [Chisholm et al., 2001]. Telephone reminders have also been used to promote medication and appointment adherence rates [Stuart et al., 2003; Ritchie et al., 2000].

Poor adherence is more frequent when the treatment is preventive rather than curative, especially when the condition is largely asymptomatic [Rand, 1993], and benefits relates to reduction in risks of future consequences (e.g. stroke) that are not directly visible to the patient. Due to the prevalence of the conditions and the demonstrated evidence of health benefits of drug treatments, the current study will focus on populations of patients receiving new prescriptions in hypertension and dyslipidemia.

2.4.2. Adherence with Lipid-lowering or Antihypertensive Agents

Adherence with chronic medications is well documented, especially in hypertension which is often a model for medication adherence. About 50 million individuals in the United States and approximately 1 billion worldwide are affected with hypertension [National Heart, Lung, and Blood Institute, 2003]. An estimated 50% drop out of care, and two-thirds remain on treatment achieve blood pressure control related to their sufficient adherence [Dunbar-Jacob, Dwyer 1991; Vermeire et al., 2001]. Based on electronic monitoring records, patients take approximately 50-90% of doses, although the overall range is 0-100% [Cramer, 2003]. In elderly patients with newly prescribed antihypertensive regimens, prescriptions were filled for sufficient medication to cover only 49% of days during the first year [Monane 1996]. Non-

adherence can reduce the health benefit of hypertension treatment since adherence correlates significantly with ambulatory diastolic blood pressure [Burnier, 2001]. Several factors are reported to increase non-adherence: patients may misunderstand the condition or treatment, deny the illness due to a lack of symptoms or perception of drugs as symbols of illness, lack of involvement in care plan, and may face unexpected adverse drug reactions [Hill, Miller, 1996].

Adherence was also well studied in patients with dyslipidemia [Cramer 2002, LaRosa 2000]. Half of patients with dyslipidemia discontinued their treatment within 5 years [Avorn, 1998], although they are likely to need it for many years, if not the rest of their lives (National Cholesterol Education Program, 1994). Other reports are even more drastic with discontinuation rates predicted to be 50% after only one year and 85% by the end of two years [Insull 1997]. Another study using retrospective data showed that only 37% of patients adhered to their lipid-lowering treatment during the 2-year study period at a level of taking at least 90% of all doses [Sung 1998]. An additional 38% of patients were non-persistent and discontinued drug therapy completely at the end of the 2-year period [Sung 1998]. When evaluating patients who received newly prescribed medications, non-persistence is also a concern as it is in clinical trials [LaRosa 2000]. In new users, discontinuation depended on the type of drug class used and was sooner among members of health maintenance organizations (HMO) [Andrade 1995]. On average, about one third of all HMO patients discontinued their drug regimen within 190 days (n=2369, 2 HMO, vs. 30 published clinical trials), which is a greater rate than in clinical trials [Andrade 1995]. The only HMG-CoA reductase inhibitor used in this analysis showed higher persistence rate than the other classes (see Table 2.3) [Andrade 1995; LaRosa 2000]. Compared to those with only hyper-cholesterolemia, patients with co-morbidities (diabetes, hypertension, coronary artery disease) have a greater adherence [Avorn, 1998]. There are also concerns that patients having received a prescription would not filled or refilled it at all. The proportion is unknown but assumed to be high [Cramer 2003].

Table 2.3 Discontinuation by Drug Class After One Year.

Drug	% HMO Patients	% Trial Patients
Bile acid sequestrants	41	31
Niacin	46	4
Lovastatin	15	16
Gemfibrozil	37	15

Data from Andrade et al., 1995; Reproduced from LaRosa and LaRosa, 2000.

2.4.3. Adherence and eHealth

Lack of knowledge is often cited as a reason for people to stop taking their medication or not taking it correctly [Fincham and Wertheimer, 1985; Donovan, 1995; Berg et al., 1993; U.S. Department, Office of Inspector General, 1990; LaRosa, LaRosa 2000]. In familial hypercholesterolemia, patients need to be convinced that their lipid-lowering treatment is necessary in order to ensure good adherence [Rand 1993]. An integrated team approach (e.g., physicians, nurse case managers, and other nurses, physician assistants, pharmacists, dentists, registered dietitians, optometrists, and podiatrists) is necessary to influence and reinforce instruction to improve patients' lifestyles and health outcomes [Hill, Miller, 1996]. The development and implementation of eHealth technologies should assist health professionals in this mission. Whether Internet health information can help or not people to be convinced about their treatment and how eHealth information influences their beliefs, attitudes, and adherence behaviors are unknown.

2.5. Theoretical Framework

2.5.1 Theory of Reasoned Action

2.5.1.1. Overview

The strength of a person's intention to perform a behavior is the primary determinant of performing a given behavior [Fishbein and Ajzen, 1975; Ajzen and Fishbein, 1980]. According to the Fishbein & Ajzen's Theory of Reasoned Action, two factors determine this intention to perform a given behavior: 1) the person's attitude toward performing the behavior, and/or 2) the person's subjective norm concerning the behavior. The theory assumes that a person takes rational decisions based on information and beliefs about the behavior. The person's attitude can be positive or negative about personally taking action, while the subjective norm relates to the person's perception that other people think that he or she should or should not perform the behavior. A person develops attitude depending on her behavioral beliefs that performing the behavior will lead to some outcomes, and also, the value and importance of these outcomes. The person's subjective norm depends on normative beliefs and motivation to comply.

The theory was later modified, and named Theory of Planned Behavior [Ajzen, 1988], to add the component perceived behavioral control. This factor, defined as "the person's belief as to how easy or difficult performance of the behavior is likely to be" [Ajzen and Madden, 1986, p.457], influences behavior both directly and through its influence on intentions.

2.5.1.2. Domains applied

This theory has been helpful in explaining various health behavior changes such as smoking cessation, weight loss [Schifter, Ajzen, 1985], exercise, safe sex behavior but also behaviors unrelated to health such as attending college classes [Ajzen and Madden, 1986]. To our knowledge, this behavioral theory has not been used in the context of Internet utilization or health information seeking behavior.

2.5.1.3. Norm, Attitudes, Internet Use and Health Care

Several components from the Theory of Reasoned Action can be observed in reports on people's health information seeking behavior. For example, people diagnosed with cancer began using the Internet to seek information about their disease following the advice of their family members [Fleisher et al., 2002]. Although physicians reported that they suggested specific Web sites to their patients [Boyer et al., 2002], we do not know if patients followed their advice. Many health professionals and researchers are concerned about the accuracy and trustworthiness of the information that can be found online [Eng et al., 1998; Coiera 1998; Silberg, Lundberg 1997; Sonnenberg 1997; Wyatt 1997; Impicciatore et al., 1997]. Others reported positive attitude toward patient's eHealth seeking behavior [Tate et al., 2003; McKay et al., 2001; Boyer et al., 2002]. Patients also reported accuracy and trustworthiness of information as the top issues concerning health information on the Internet [Boyer et al., 2002; Murray et al., 2003]. However, when finding unsatisfactory information, they act to seek other sources online [Boyer et al., 2002]. They have an overall positive attitude towards the health information online and reported having found it useful and influential when taking health-related decisions [Baker et al., 2003; Murray et al., 2003].

2.5.2. Social Cognitive Theory

Based on the social cognitive theory, people with strong self-efficacy in using the Internet to find health information will be more likely to access it [Fleisher et al., 2002; Eastin, Larose, 2000]. Also, people having a strong confidence in their potential to take control over their disease will be more likely to seek information.

2.5.2.1. Overview

The three primary factors that determine the likelihood that a person will adopt a health behavior change are: 1) self-efficacy, 2) goals, and 3) outcome expectancies (Bandura, 1977b,

1986, 1997a). This is the Social Cognitive Theory by which behaviors are essentially linked to the person's confidence or self-efficacy in performing a desired behavior change even if there are barriers. The person evaluates the expected outcomes that include the physical effects, social costs and benefits, and positive and negative self-evaluative reaction to a health behavior. The person's value system shapes his or her goals that give self-incentives to perform the health behavior. Humans learn from experience; the "enactive learning" (as named by Bandura) is performed by observing others or self-monitoring (Bandura, 1997, 1991b). The person continually reforms expectations about the behavior.

2.5.2.2. Domains Applied

The Social Cognitive Theory has been applied to Internet usage (Larose et al., 2001) and to general computer usage [Compeau and Higgins, 1995, Compeau et al., 1999]. Self-efficacy and professional outcome expectations explained 34% of the variance in usage of computers [Compeau and Higgins, 1995]. The expectations about the positive outcomes (encountering informative Web pages or making social contacts), and the negative outcomes (computer freeze up while surfing the Web), as well as Internet self-efficacy [Eastin and Larose, 2000] can determine the use of the Internet [Larose et al., 2001]. Internet self-efficacy is positively related to Internet usage, independently of the effects of outcome expectations ($r=.65$, $p<.001$) [Larose et al., 2001].

Activity outcomes ($r=0.48$, $p<0.001$), pleasing sensory outcomes ($r=0.37$, $p<0.001$), novel sensory outcomes also termed *informational dimension* ($r=0.32$, $p<0.001$), social outcomes ($r=0.37$, $p<0.001$) and negative Internet outcomes ($r= -0.16$, $p<0.05$) were all related to Internet usage [Larose et al., 2001]. The combination of these variables significantly predicted Internet usage ($F_{9,168} = 26.512$, $R^2=0.60$, $p<0.001$). Internet self-efficacy was the most powerful predictor of Internet usage ($b=0.652$, $R^2_{\text{change}} = 0.425$, $p<0.0001$). Perceived addiction ($b=0.4111$, $R^2_{\text{change}} = 0.114$), activity outcomes ($b=0.208$, $R^2_{\text{change}} = 0.035$), and self-

disparagement ($b=-0.013$) each uniquely predicted Internet usage ($p<0.05$) [Larose, 2001]. Their study relied on a convenient sample of college students who retrospectively self-reported their Internet use and kept a diary of their total Internet use ($r=0.65$, p not reported). As they commented, their results differ from a previous report where the informational dimension (termed *novel sensory expectations*) was the most powerful predictor of Internet usage [Charney and Greenberg, 2001]. They proposed an explanation for the difference as being due to the change in character of the Internet perceived as a source of enjoyable activities rather than a repository of information [Larose, 2001]. The convenient sample of college students may also had an influence on the results of this previous study [Larose, 2001], and further evaluation of a different population would bring generalizability.

2.5.3 Theoretical Framework & eHealth Behaviors

Ajzen's "perceived behavioral control" (1988) is similar to Bandura's "perceived self-efficacy" (1986) because they both depend on a person's beliefs of having the resources and opportunities to perform a behavior or reach a goal [Maddux and DuCharme, 1997, p.135]

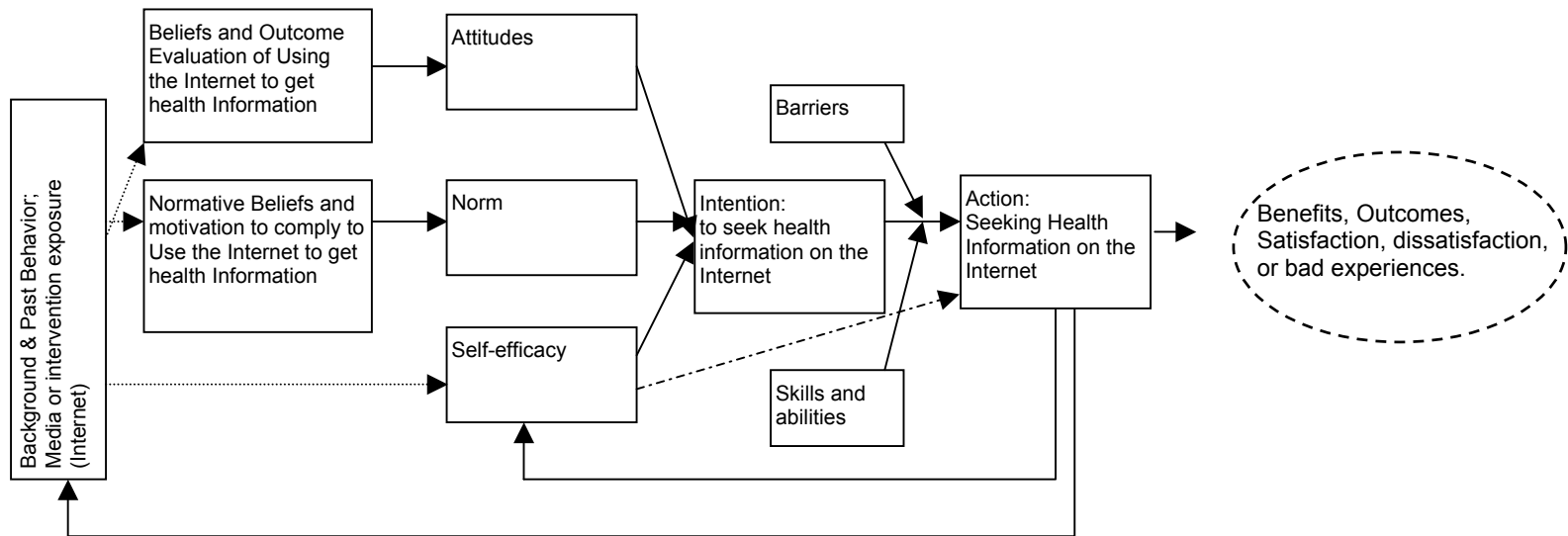


Fig. 2.1 Theoretical Framework

Adapted from the Committee on Communication for Behavior Changes in the 21st Century, Scrimshaw S, Bandura A, Fishbein M, et al. 2002

2.5.4 *Summary related to this research project*

The selected model conceptualizes the use of Internet to access health information based on self-efficacy and information needs. Example of benefits or outcomes can be an increased knowledge about the disease and drug treatment that retroactively can increase a person's sense of control in their health care decisions. With Internet access, people may have reduced perceived barriers to access information and a favorable attitude toward health information found online.

An increased knowledge and control in their health care decision can in turn lead to improved health behaviors including adherence to drug therapy, relationship with health care professionals and overall satisfaction with pharmaceutical care services.

2.6. Summary of the Proposed Research

This study was based on the theoretical framework of the social cognitive theory with the exploratory evaluation of basic psychometrics properties of an eHealth seeking self-efficacy measure. Measurements were obtained with self-administered surveys and direct observations (log files) of eHealth use. A Web site was created for this project to guide people to eHealth information and to monitor usage. The study Web portal (www.RxLinx.org) presented links to selected drug-specific Web sites to participants in the intervention group. Patients taking prescription medications for dyslipidemia, hypertension or diabetes were recruited in different locations. Volunteers were randomly assigned to either the control group or the intervention group. Participants in the intervention group were asked to seek health information using the study Web portal. The control group was assumed to receive routine information care.

The results of this study brought knowledge on people's needs for supplemental information about drug treatment, their attitudes toward the Internet as a source of health information, and the impact of this utilization on communication with pharmacists, and on the patient's knowledge about the disease and its treatment.

2.7. Significance

Millions of citizens seek health information on the Internet each day and little is known about the impact of this behavior on their health and health decisions. There is a demand for more information, and clinicians should not underestimate the potential benefits of incorporating eHealth information in medical or pharmaceutical practice. Information systems have been integrated in health care settings, and patients as well as health professionals use the Internet to access health information. The Internet as a medium of health information may integrate the provision of care through counseling and patient self-education. This transformation in practice needs further investigation before giving any recommendations as how to best integrate the use of Web health information into health care practice.

An information gap currently exists when consumers receive a new diagnosis or prescription medication. Health professionals do not have enough time and resources to fill this information gap and implement health education programs. On the other hand, patients have an interest in learning more about their health and take greater control but are not being encouraged to self-educate and gain conviction that they are able to seek eHealth information.

The existing eHealth information and services provided free by the government, medical associations and pharmaceutical manufacturers are not being used optimally for provision of health education.

The non-adherence to medications, such as anti-hypertensives and lipid lowering agents, is a public health concern affecting million of patients in need of medication treatments. Various interventions need to be investigated to bring cost-effective solutions to non-adherence.

With this research, there will be a gain in understanding of the impact of eHealth use as part of pharmaceutical care and patients' self-education, which has great potential for public health value. Supplemental health information can benefit society by creating a greater awareness of side effects, increase patient involvement in their health care, increase knowledge

of prescribed treatments and disease, improve adherence to drug treatments, and increase communication with health professionals.

Health professionals will gain from having more knowledgeable patients empowered with information. Patients can gain from being more involved in their care, being partners in decision making, as well as for the monitoring of side effects and optimization of treatment with an adequate choice and dosage. Pharmaceutical companies can gain from having better usage of their product accordingly to the approved indications as followed by the patients.

In summary, the significance of this project is twofold: gaining understanding of the impact of the use of eHealth by million of citizens, and evaluating a potential solution to the problem of non-adherence to medication through the use of eHealth information in self-education.

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CHAPTER 3

RATIONALE, OPERATIONAL DEFINITIONS, AND HYPOTHESES

3.1. Research Problem, Research Questions, and Rationale

3.1.1. The Public Health Problem

Health professionals estimate that about 75% of medications are taken as prescribed in a variety of diseases (Cramer, 1989; Cramer 2003). Up to 50% of patients with high blood pressure or dyslipidemia necessitating drug therapy drop out of care [Dunbar-Jacob, Dwyer 1991; Avorn 1998]. The overall cost due to non-adherence to treatment is estimated to be greater than \$100 billion [National Pharmaceutical Council, 1994]. Many factors influence patients deciding to stop their treatments. Patients' lack of beliefs in the medication benefits and lack of information are two important determinants of adherence [Fincham and Wertheimer, 1985]. When patients receive a newly prescribed medication for a chronic disease, they obtain limited information regarding the drug and the disease from health care professionals. This leads to ask the question: does stimulating self-learning experiences about their drug treatment convince patients to adequately take their medications?

3.1.2. Limitations of the Actual Sources of Health Information

Both physicians and pharmacists provide a brief form of patient counseling, mostly about the product. Health care professionals are open for further questions but have limited time for patients' requests for further explanations. Drug labeling and mandatory medication guides regulated by the FDA also provide information to patients about their medication. Some supplemental information can be provided about the disease through leaflets developed by pharmaceutical companies, health plans, associations or pharmacists.

Although some information can be offered at the point-of-care, patients' learning is not optimized due to negative attitudes towards counseling, lack of awareness and barriers to access of information. For example, patients may not welcome the information offered. In fact, customers can sign a refusal for counseling. Patients accepting the information may not be able to read the patient information or medication guide [Graham, 2000; Anon. Community Pharm, 2001, 2003]. Additional resources such as brochures may not be picked up by the patients because they are unaware of the availability of information. Patients may argue that they do not have time at the point-of-care for more education, or that they are not interested by the information. New forms of patient education available on the Internet may help reach patients and stimulate them to be more involve in self-education.

Limits exist in the provision of comprehensive patient education by health professionals. Due to workload related to dispensing tasks and lack of financial compensation for cognitive services, an opportunity to instruct patients about their disease is not fully optimized when a prescription is filled at a pharmacy. The pharmacist has a privileged position to encourage patients to participate in self-education about their medications and diseases.

3.1.3. The Patient's Exposure to Health Information

Some patients take the initiative to seek out supplemental health information. Demand for prescription medication information has been growing as drugs have played a greater role in the treatment of diseases. Access to health information by people seeking further data is limited; often veiled by and restricted to health professionals. However, the demand for books such as the Physician's Desk Reference (PDR), Dr. Spock's bestseller and others, and now the use of Internet health resources shows clearly that the public is interested in learning more about health care.

By the end of the 1980s, one of the first direct-to-consumer advertisements for prescription medication in the United States had raised public interest for medication

information. Since then, there has been an increasing passive exposure to drug advertising and disease information. The commercial nature of this type of information is not without concerns of potential biases. At present, the Internet is another source of health information easily accessible.

Patients have shown a growing interest in taking an active part in their health care. The individual most responsible for his/her own health care, the patient, is the least informed [Fincham and Wertheimer, 1985]. Responsibility for learning relies on the patients to take action to educate themselves. However, pharmacists have a role to guide patients toward reliable, current and unbiased online information [Pankaskie, 2002].

3.1.4. The Internet as a Source of Health Information

Most U.S. citizens (> 60%) have been adopting Internet technology and many (30-40%) use it to access health-related information [Horrigan and Rainie, 2002; Baker et al., 2003; Murray et al., 2003]. Compared to advertising, the use of Internet takes more effort by patients, and may imply an active learning behavior. At least 30% of Americans have looked on the Internet for health information in the last 12 months [Murray, 2003]. Half of them self-reported discussing Internet health information with their doctor [Murray, 2003]. About one third of Internet users self-reported that using the Internet for health purposes has influenced them in their health decisions [Baker, 2003]. However, almost all of consumers reported that Internet use had no effect on the number of visits (94%) or telephone contacts with their physician (93%) [Baker, 2003]. Little is known regarding the impact of the use of the Internet on patient's health decisions or outcomes. We do not know how eHealth usage influences patients' decisions related to taking their medicine.

An enormous amount of comprehensive educational health material is available on the Web to those who can access the Internet. In the United States, most national organizations and government agencies, in addition to commercial groups and pharmaceutical companies

have been investing millions of dollars to develop health-related Web sites providing information about diseases, treatments, prevention programs, risk assessment tools, and other interactive services.

3.1.5. A Guiding Role for Health Professionals

Although great resources exist online, there is no formal integration of the use of the Internet for patient education by health professionals. This situation may be considered as sub-optimal since health information resources are available but not integrated in practice in the form of health education. Patient education has shown benefits in health outcomes in several studies, and is even considered as a necessary part of the minimal standard care for the diabetic population (American Diabetes Association's recommendations, 2003). Most pharmaceutical manufacturers make an effort to provide patient information and Web resources related to their brands. When a medication is prescribed, health professionals should promote lifestyle modifications such as smoking cessation, change in diet, weight loss and increased physical activities to provide further health benefits and reduce complications. Health education has proven benefits but professionals have limited resources and time to provide it to everyone. By encouraging patients to have self-learning experiences, pharmacists may contribute to augment patients' self-efficacy in using the Internet for health education and in taking better care of themselves.

Based on the theoretical model of behavior change, several factors such as attitudes, norm and self-efficacy can explain why a person builds an intention or takes action. The following framework will be applied to shape the present study. The impact of the eHealth behavior may or may not be visible to the individual such as the process observation of adherence, provider-patient interaction and knowledge. However, these are part of the retroactive feedback within background and past behavior which further affect the personal beliefs and the outcome evaluation of performing the behavior. The path analysis of the model

presented in Figure 2.1 will not be tested globally. The current study will mainly focus on some outcomes expected from performing the eHealth behavior (adherence, knowledge, patient-practitioner interaction). The rest of the model will be partially tested with a focus on eHealth self-efficacy relationship with eHealth seeking behavior.

3.1.6 Summary and Research Questions

Non-adherence is a major public health problem that requires attention (Healthy People 2000/2010). There are limits to the provision of health education and comprehensiveness of information to all patients needing it. Further, patients want more information and have an interest in seeking eHealth information. Finally, health professionals may benefit from the use of eHealth resources such as information systems to help them in the provision of cares.

Based on these facts, there is a need for investigating a potential solution to the adherence problem and probable benefits of eHealth information. An essential question arises: Does the use of Internet for self-education about medications and diseases have an impact on patients' health behavior and outcomes? To investigate this issue, we will consider the following questions:

- Do patients seeking eHealth information adhere differently to their prescribed medications than patients not seeking eHealth resources?
- Do patients seeking eHealth resources learn about their disease and medications?
- What are patients' attitudes towards the use of eHealth information such as prescribed medications and diseases information?

3.2. Operational Definitions, Definitions and Hypotheses

This study to develop a better understanding of the impact of 'eHealth information Seeking' on patients who take prescribed medications for chronic diseases. The specific aim is to determine the impact of 'eHealth Seeking Behavior' on: medication adherence, disease knowledge, attitudes, and patient-practitioner interactions. Five main areas will be considered in this project: 1) health-related processes and outcomes, 2) eHealth self-efficacy, 3) eHealth and Internet usage, 4) patient-practitioner relationship, and 5) knowledge.

Conceptual Definitions:

Routine pharmacy practice: This concept is defined as the typical care provided by a pharmacist dispensing a prescribed medication. Pharmaceutical care is "the responsible provision of drug therapy for the purpose of achieving definite outcomes that improve a patient's quality of life" [Hepler and Strand, 1990; Malone et al., 2001]. Pharmacists may provide verbal or written information about the drug; the dosage, the main side effects; cautions, food or drug interactions, and answer patient questions. For the purpose of this project, no special training or guidance will be provided to pharmacists. There will be an assumption that participants' pharmacists have a typical pharmacy practice.

eHealth: This concept is defined as "an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology". [Eysenbach, 2001]

eHealth Information Seeking Behavior: Citizens around the world are accessing the Internet and related technologies in different ways to seek drug-, disease, or health-related information or services. This behavior will be defined as “eHealth information Seeking Behavior”. People can perform this behavior by accessing the Internet using desktop or portable computers, mobile devices such as handheld computers or cellular phones, or less widely distributed Web-TV or web-enabled touchscreen kiosks. Users access the Internet using these devices from home; work; public places; at the point-of-healthcare or anywhere they need it with mobile technology.

3.2.1. eHealth Self-efficacy

Based on the theoretical framework previously presented (Fig. 2.1), a person modifies his/her own attitudes, beliefs and expectations, and also his/her conviction in performing the task through experience. In this controlled study, the participants in the intervention group accessed information about their prescribed medication or conditions. By accessing eHealth information (action) about their medications the person should build new attitudes toward eHealth information that may influence future behaviors and outcomes expectancies.

Behaviors are essentially linked to the person’s self-efficacy in performing a desired behavior change even if there are barriers (Bandura, 1977b, 1986, 1997a). Perceived self-efficacy is not a measure of skills the person has, but what the person believes she/he can do under different sets of conditions [Bandura, 1997a]. Based on the social cognitive theory, people with strong self-efficacy for using the Internet to find health information will be more likely to perform and persevere in their information seeking behavior when facing difficulties. There is an “enactive learning” (as named by Bandura) that is learning from experience by observing others or self-monitoring (Bandura, 1997, 1991b). In addition, the person continually reforms expectations about the behavior. Through performing the behavior (eHealth Seeking), the

person's self-efficacy can change; therefore people may gain confidence in their capability to find information on the Internet.

The first set of hypotheses related to the evaluation of nomological validity of the eHealth information seeking self-efficacy scale. To avoid redundancy, most operational definitions are mentioned in Chapter 5.

H_{A1}: There is a significant relationship between eHealth self-efficacy and eHealth use.

H_{A2}: There is a significant and positive relationship between eHealth self-efficacy and Personal Information Outcomes Expectancy.

H_{A3}: There is a significant and positive relationship between eHealth self-efficacy and general Web browsing self-efficacy.

H_{A4}: There is a significant and negative relationship between eHealth self-efficacy and Computer Anxiety.

A detailed description is presented in Chapter 5. Operational definitions of each constructs are presented in the Chapter 5.

eHealth self-efficacy: This variable is a measure of the patient's conviction that he/she can use the Internet to seek health information. An instrument was created based on previous scales measuring the construct *Internet Self-efficacy* and *Computer Self-efficacy* that is defined as the patient's conviction that he/she can use the Internet or computers, respectively.

Personal Information Outcome Expectancy: This construct is assessed with a scale measuring the likelihood of finding immediate information on the Internet. A summated score was computed with responses on the 5-point Likert-type scale (1-very unlikely, 5-very likely). The scale has support for reliability with a Cronbach's Alpha of 0.87 [Charney and Greenberg cited in Eastin and Larose 2000].

3.2.2 Medication Adherence and eHealth information seeking

Patients' lack of belief in medication benefits and lack of information about a drug are two of the most important determinants of medication adherence [Fincham and Wertheimer, 1985]. As the Internet can be seen as an additional path to gain health knowledge, it is reasonable to believe that there could be a relationship between the use of eHealth and medication adherence. This is assuming that Internet information seekers will act following the exposure to eHealth information or change their beliefs consequently to their findings.

The Social Cognitive Theory has also been applied in research about adherence to prescribed drug treatments. Adherence self-efficacy explains part of medication adherence behaviors; therefore led to another hypothesis. A question was raised: is there any relationship between eHealth information seeking and medication adherence? This question was assessed with the following hypotheses.

H_{A5}: There is a significant relationship between eHealth seeking intensity and medication adherence controlling for adherence self-efficacy

H_{A6}: Internet-user patients prompted to do 'eHealth information seeking' will have a significantly different medication adherence than Internet-user patients who only receive routine pharmacy services.

Medication Adherence: A self-reported measure of medication adherence named *Hill-Bone Compliance scale* was used in this study (Kim, Hill, Bone, 1999). This scale was adapted to be specific to hypertension, high cholesterol or diabetes treatment. A total summated score (range 8-32) of the eight 4-point Likert-type responses (1=None of the time, 2=Some of the time, 3=Most of the time, 4=All of the time) was computed for each respondent as an estimate of their medication adherence. A higher score indicates a poorer adherence. (See Appendix N, item #9)

Adherence Self-efficacy: This construct is defined as the patient's conviction that he/she can take control of taking medication as prescribed. A 5-point Likert-type scale (1=strongly disagree, 2=disagree, 3=neutral, 4=agree, 5=strongly agree) was selected due to its level of evidence of reliability (Chronbach's alpha = 0.87) and validity assessing how confident are respondents in being able to comply or how tempted they would be to not comply. [Cook CL, 2002] The summated score (range between 5-25) will provide a measure of the potential for non-adherent behavior. A higher score indicates a poorer adherence. (See Appendix N, item #10)

eHealth Use: A direct measure was the frequency of logins to the study Web directory during the 2-month study period. The total time spent and the number of external links primarily accessed will also be collected for exploratory purpose. All of these measures will be automatically recorded through Web site's log for each individual identified with a username during login. A second measure will be a single-item 5-point Likert-type scale asking the participants how frequently they sought eHealth information related to their medications or diseases (5=Very often, 4=Often, 3=Occasionally, 2=Rarely (at least once), 1=Never). (See Appendix N, item #30)

3.2.3. Knowledge and eHealth

Through the exposure to eHealth information, people will have beliefs about performing the information seeking behavior and will expect outcomes from performing this action. The person may be affected by some sources of information that have a normative influence (pharmaceutical companies, governmental or national groups, as well as other patients affected with the disease). Exposure to eHealth information may be an additional pathway for patient education and learning. The next hypothesis evaluates the impact of eHealth seeking on patient knowledge.

H_{A7}: Internet-user patients prompted to do 'eHealth seeking' will **have significantly different disease-related knowledge** than Internet-user patients only receiving routine pharmacy services.

General Knowledge: There was 4 items assessing knowledge about medication in general (2 items), and about cardiovascular diseases (2 items). These items assessed knowledge about stroke, myocardial infarction, and side effects of medications and were not worded specifically for a specific disease. (See Appendix N, items #15, 19, 21, 23)

Hypertension Knowledge: Hypertension knowledge was assessed using a pre-tested questionnaire of 6 items specific to hypertension: its treatment including duration, related cardiovascular risks, physiology, biometrics, lifestyles (diet and exercise), and morbidity. (Appendix O, items #15, 19, 21, 23)

Diabetes Knowledge: Diabetes knowledge was assessed using a pre-tested questionnaire of 6 items specific to diabetes: its treatment including duration, related cardiovascular risks, physiology, biometrics, lifestyles (diet and exercise), and morbidity. (Appendix P, items #15, 19, 21, 23)

Dyslipidemia Knowledge: Dyslipidemia knowledge was assessed using a pre-tested questionnaire of 6 items specific to diabetes: its treatment including duration, related cardiovascular risks, physiology, biometrics, lifestyles (diet and exercise), and morbidity. (Appendix N, items #15, 19, 21, 23)

A composite score was created of the general knowledge and one of the disease-specific knowledge. A summated score was computed by giving two points for each correct answer for a total of 20 points. (Appendix N, Final Questionnaire, items # 49-58; and Appendix N-P, Diabetes, High Cholesterol, Hypertension Knowledge Questionnaires)

Perceived Learning: A 6-item measure of self-reported learning was developed and tested for internal reliability. The 5-point Likert-type scale (1= strongly disagree, 2=disagree,

3=neutral, 4=agree, 5=strongly agree) was summated and scoring ranged from 5-30, where a higher score indicated higher Perceived Learning. Another single open-ended item asked respondent to report and describe if there was something important to them that was learned during the period of the study. (Appendix N, Final Questionnaire, items # 8 and 35).

3.2.3. *Patient-practitioner relationships and eHealth*

The use of eHealth information or information provided by direct-to-consumer advertising is often cited to promote patient's empowerment by taking a greater role in the decision-making process [Perri et al., 1999; Fleisher et al., 2002]. Direct-to-consumer advertising of prescription drugs is also believed to impact the physician-patient relationship [Anderson, 2003]. Patients may find on the Internet drug interactions [Anderson, 2002; 2003], or learn about side effects to report to a health care professional. Empowered with more information, patients can take part in the decision-making process with their health care providers [Wallerstein, 1992; Funnell et al., 1991; Roberts 1999; Trevitt et al., 2001; Kim, Lehmann, 2003; Zablocki, 1998]. The operational definitions related to the following hypothesis are presented below.

H_{A8}: Internet-user patients prompted to do 'eHealth seeking' will have a significantly different level of patient-provider relationship than Internet-user patients receiving routine pharmacy services.

Level of patient-provider relationship: The level of relationship was estimated in two ways: through the "Communication with the pharmacist" and through the "Intention to communicate eHealth findings with a health provider", defined below:

Communication with the pharmacist: A single item assessed if the patient asked the pharmacist any question the last time he or she refilled prescriptions for high cholesterol, hypertension and/or diabetes. This item was coded as 0- no questions or did not talk to the

pharmacist, 1- one question, 2- more than one question. (Appendix N, Final Questionnaire, item #29)

Intention to communicate eHealth findings with a health provider: The intention will be estimated based on the self-report of the collection of printed pages from the Web with the intention to show to, and discuss with a health professional. Participants who report one of these behaviors will be considered having an intention to communicate with a health care professional. (Appendix N, Final Questionnaire, item #30)

CHAPTER 4

STUDY DESIGN AND METHODS

4.1 Summary

The study population consisted of patients having Internet access and taking prescribed antihypertensive, lipid-lowering agents and/or diabetes medication. Participants were recruited in pharmacies (3 chain stores and 4 independent pharmacies), at an adult and Cardiac Rehabilitation Fitness Center in Athens, a senior group and a large multinational corporate headquarters located in Atlanta. Volunteer were randomized to either the control group or the eHealth information intervention group.

Participants in the intervention group were prompted to access a Web portal to get supplemental eHealth information 4 times during the 2-month study period. Participants were reminded by email every 7 to 10 days to access the Web site. They could access the Web site as frequently as they needed. Instructions contained in the research material requested patients randomized to the intervention group to seek eHealth information on the study Web portal. It was assumed that the control group received only routine pharmacy services and information provided by the pharmacist and/or by a pharmacy technician when prescribed medications were refilled.

The portal linked to eHealth information sources and tracked usage by participants over 2-month period. The Web directory was created to link to existing Internet resources on prescription drug information provided by governmental, non-governmental, and commercial entities as well as by the pharmaceutical manufacturers. A paper-based baseline survey was used, and an Internet-based post-test instrument assessed several measures including medication adherence, disease knowledge, self-efficacy, and eHealth use.

4.2. Design

4.2.1. Research Design & Data Collection

This study was a randomized controlled trial. Randomization followed a random permuted blocks method that allowed the allocation of an equal number of patients to each of the two treatment groups (eHealth Intervention or Control). This method was chosen to reduce guessing of the next assignment group by the recruiter, which can introduce selection bias. [Gore, 1981a, 1981b; Roberts and Torgerson, BMJ 1998; Altman and Bland, 1999]

Eligible volunteers were given a pre-randomized, pre-identified numbered and sealed envelope containing consent forms, the baseline paper-based survey and other research material. A pre-paid returned envelope was later included in the packages to increase rates of returns of consent forms when people did not complete the forms on site. The second and final survey was sent to the participants after 10 weeks, allowing most patients to get two refills assuming adherence to prescribed medication. The link to the survey was first sent by email (online version developed using phpSurvey 2.0) with a follow up reminder sent 3 days later. Participants were contacted by telephone to increase awareness of email being sent, and ask if they would rather receive a paper format.

The adherence self-efficacy and knowledge constructs were measured at the end of the study period. Baseline measures included demographics, previous eHealth information use, Internet use, and eHealth self-efficacy. The usage of the study Web portal (intervention group only) will also be continuously collected. Individual email reminders were sent to the study participants every 7 to 10 days to invite them to visit the Web portal as requested 4 times, or more if needed. Reminders were not sent anymore when a participant emailed us saying that he or she had already visited 4 times. This was verified with the real time log of the Web portal. The control group received one email at the beginning of the study to thank them for their participation and remind them to complete and return the first survey (as in the first email to the intervention group participants).

4.2.2. *The Web Intervention*

In this study, the intervention was limited to ask patients to use a study Web portal 4 times during the 2-month period. The development and content of the study Web portal are presented in details later in this document. Briefly, it guided users to a sample of health Web sites that present drug-related or disease-specific Web pages.

The task assignment of seeking eHealth will be provided to the patient in the study material to prevent confounding influences from the pharmacist giving attention to the patients randomized to the intervention group. Follow up by email will be done to both groups (control and intervention) to confirm participation into the research study (control) and remind the intervention group to log to the study Web portal.

Perceived barriers or actual constraints (such as not having access to the Internet, or having difficulties finding information online) can jeopardize a person's intention to act. To reduce this barrier, the participants in the intervention group was provided with access to the study Web portal as a way to easy access to direct sources of eHealth information and facilitate eHealth seeking behavior.

Participants were free to access the study Web portal from any location: home, work, a friend's or relative's house, or a public place (library, café, etc.).

The access to the study Web portal was done only through an individual login and password access provided to the participant in the research material. A brief reminder (business-card size) was given to the participant with the Web site URL (<http://www.RxLinx.org>) and their individual identification information. A dummy password was provided in study participants' individual research package. No subject was aware that the password was the same for all packages. Participants selected their username following the instructions: LASTNAME## (where ## was replaced by the last two digits of their birth year). This allowed a simple login feature with the ability to identify individual users. No guest access was allowed to avoid contamination of the control group with a potential access to the Web portal.

4.3. Methods

4.3.1 Sample Size

Power Analysis

A meta-analysis summarized the results of 153 studies that evaluated the effectiveness of interventions to improve patient adherence [Roter et al., 1998]. The magnitude of the effects range from small to large on adherence indicators. The intervention in the current study may be classified as educational in nature (not behavioral or affective). The expected effect size of this type of intervention was reported to be 0.28-0.35 for indirect adherence measure studies (prescription refills) and 0.14-0.20 for subjective measures (self-report) [Roter et al., 1998]. The effect size rises above 0.40 when the intervention involved the provider (indirect measure of adherence). The effectiveness of intervention channel was also evaluated. Interventions with written educational material had a small effect size (0.12) while group education or one-to-one interventions have a medium effect of about 0.30 to 0.40 (direct or indirect measure of adherence). The authors also evaluated the effectiveness of interventions on knowledge outcomes [Roter et al., 1998]. A range from moderate to significant was noted (0.31 to 0.60) and varies across the diagnostic categories. Medium effects were reported in hypertension interventions (0.32).

Based on the previous information, an effect size of 0.30 was considered for the type of intervention that will use written material but may involve the pharmacist through discussion about educational online materials. It is unknown if the visual attractiveness or interactivity of the Web content may influence the effectiveness.

Providing a power of 70% ($1-\beta=0.70$) for 95% confidence ($\alpha_2=0.05$) and a medium expected effect size ($d=0.30$), a sample of size 140 participants in each group would be required [Cohen, 1977]. In these same conditions, if the effect size is larger at 0.40, a sample size of 80 participants in each group would be needed.

Although participating sites' volume of prescriptions should have been possible to recruit larger number of participant, after 2-week period, the recruitment of patients receiving newly prescribed drugs only in pharmacy was an issue. The protocol was then changed to include any patients with a prescription for the selected diseases. Again, the recruitment was a problem. To obtain larger number of participants, other sites were found to reach our target population of Internet-users taking prescribed medications.

4.3.2 Study Population

Patients taking prescribed medications from one or more of the following classes: anti-hyperglycemic and hypoglycemic agents, cholesterol lowering agents and/or antihypertensives. Patients were invited to participate if they self-report having access to the Internet and taking prescribed medications for one or more of the three conditions. The pre-screening questions were asked by a pharmacy technician, or the principal investigator, and recorded anonymously for non-participants (Appendix K).

4.3.3. Investigational Review Board (IRB) Approval and Health Insurance Portability and Accountability Act (HIPAA) Compliance

This research project was in accordance with the University of Georgia's Human Subjects Research Office and the Health Insurance Portability and Accountability Act of 1996. Signed consent forms were obtained from the volunteers as approved by the Institutional Review Board and in compliance with HIPAA regulations (Appendix E and F).

In order to assure the respect of privacy and confidentiality of medical information collected during this research project and shared from the pharmacy records, a separate "Authorization to Use & Disclose Health Information Form " including an acknowledgement of receipt of the "Notice of Privacy" was signed by the patients for the release of their medical information to the investigators. Agreement between a representative of the pharmacy, district

or local pharmacy or chain managers, the health promotion specialist at the Atlanta headquarter, and the principal investigator were signed and filed as part of the IRB dossier.

All databases, files and paper questionnaires will be kept confidential in a password protected computer drive or in a locked cabinet. Personal identifiers, including medical information and IP address, will be removed from the files before statistical analyses. The name of the company will be kept confidential.

4.3.4. Inclusion/Exclusion Criteria

Participants were eligible if they volunteer and met the following criteria.

Inclusion criteria: Patients were eligible to participate if they had the following required characteristics: self-reported taking prescribed medication in one or more of the target diseases, had Internet access, and age older than 18 year old.

Exclusion Criteria: Patients were not eligible to participate if they have the following characteristics: Being diagnosed with one of the conditions without having any medication prescribed, being functionally illiterate (self-reported), being blind, or facing physical or mental disability or mental illness (depression, psychiatric illness).

4.3.5 Duration of the study

The recruitment period was from February to May 2004. The final measurement was done after 8-10 weeks with an online or a paper version of the final questionnaire completed by the participants.

4.3.6 Additional Definitions and Operational Definitions

Due to the novelty of the eHealth research field, some aspects will be exploratory and descriptive to further understand the eHealth seeking behavior.

Direct-to-Consumer Internet information (DTCII): This concept characterized the eHealth information or health services provided online directly to consumers by pharmaceutical manufacturer about a prescription medication.

Speed of Access: Participants self-reported their type of Internet access. From less accessible to more accessible, the categories will be: (1) modem connection; (2) DSL, LAN or cable connection. (Appendix J, Baseline Questionnaire)

Internet Experience: Two items were included in the baseline questionnaire.

a)General Internet experience: Participants will answer one item assessing for how many years they have been using the Internet. This was a categorical variable (Baseline Questionnaire, item #8).

b) eHealth experience: The other item will be more specific to eHealth seeking. Participants were asked to report their type of eHealth users (ever looked for eHealth/ indirect user by having someone else providing them with eHealth information/ never looked for eHealth) frequency of eHealth usage. (Appendix J, Baseline questionnaire, items #10 and #11).

eHealth Use Duration: This variable will be operationally defined as the time in seconds between the time when an external Web page is accessed from the study Web portal, until the next action on the study Web portal, including logoff, or clicking on “close this window” of an external source’s Web page. If there is no action performed, the measure will not be taken into consideration and will be considered as missing value.

Satisfaction with health information: Three items assessed the satisfaction: with eHealth information (Appendix N, items #33), with the information received at the pharmacy either about medications or diseases (Appendix N, items #6 and 7).

Location of Access: Location where users accessed the Internet to seek health information most of the time. The categories were: (1) at home, (2) at work; (2) at home and work about equal; (3) at a public place (library or Internet Café).

Overall Health: This variable is an estimate of the person's self-evaluation of their health condition. A 5-point Likert-type item. (Appendix J, item #21)

4.3.7. Process and Timelines

Recruitment

The pharmacy technician distributed an announcement of the study to the patients coming to pick up a prescription among the selected therapies. If the technician had time, the pre-screening questions about Internet use were asked to the patients (Appendix K). If the patient was eligible, the technician gave an invitation letter to the patient. While waiting for the prescription to be filled, the patient was able to read and sign the consent forms, or returned it later by pre-paid mail or directly to the pharmacist or to the principal investigator. (Appendices E-G)

Patient meeting the eligibility criteria were told that the study included a first baseline questionnaire now and one in a later communication in 2 months. By chance, they might have been asked to look at some Web information.

Randomization of the study participant will be predetermined by ordered sealed envelope to classify patients into the intervention or control group

Study Period

The intervention group had access to the study Web portal. Every 7 to 10 days, the participants of the intervention group received an email to remind them to visit the study Web site. The control group received a thank you email confirming their participation in the study.

Survey Questionnaire

Eight to twelve weeks after recruitment, each participant received by email or by regular mail the final self-administered questionnaire (see Appendix N). The second and final survey

was sent to the participants after 10 weeks, allowing most patients to get two refills assuming adherence with prescribed medication. The link to the survey was first sent by email (online version developed using phpSurvey 2.0) with follow up reminders sent 3 and 10 days later. Participants were contacted by telephone to increase awareness of email being sent, and ask if they would rather receive a paper format. The participants who had first not provided the investigator with their email addresses were contacted by phone, then sent the survey by mail or email. Follow up phone call were done to non-respondents after one more week, and a reminder email including the link to the online survey was sent to non-respondents after 12 days.

Pharmacy Records

Permission to obtain data from the pharmacy patient records was obtained with the written agreement by each participant. Signed consent forms respected the IRB approval as well as HIPAA regulations (see Section 4.3.1 in the current chapter).

Self-administered questionnaire were used in this study. During the study, change in the protocol was necessary and pharmacy refill records was decided not to be used to assess adherence.

Internet Use

Data will be extracted from Web log files automatically until the end of the study. (See Appendix Q, Sample of Tracking Reports)

End of Study

At the end of the study, the Web site will be made available to the participants in the control group for their own curiosity and to give them access if benefits are observed from this

study. Login and password will be required to prevent public access, but no individual data will be further recorded.

4.3.8 *Data Analyses*

The data will be transferred manually from the questionnaires filled in a paper format in an MS Access database. The study portal includes internal pages with limited access to only the principal investigator to collect and observed computer logs that were being automatically recorded. A feature to create Excel spreadsheet from the Web log was developed. SQL queries were used to extract tables from the PHPsurvey administrative databases, then converted to Excel spreadsheet, further transformed in adequate format into SPSS. The statistical analyses will be done using SPSS 12.0 .

Data analysis included descriptive statistics of the sample characteristics, statistical testing using one-way ANOVA when the assumptions were met, t-tests, and non-parametric analyses for categorical variables. The reliability of scales were evaluated with Chronbach's alpha.

4.3.9 *Materials*

Study Group Materials:

Participants in the intervention group received in the study material package a reminder business-size card with login and password information to access the study Web portal. Post-it® sticker pads were provided to the intervention group presenting a reminder message "Learn every week! Drug and Disease Web information" with the URL of the Web portal: www.RxLinx.org.

The control group received a blank Post-it® pad for their convenience and a small pocket business card with a thank you note for their participation and the principal investigator's contact information.

Participants received the baseline questionnaire (paper-based with business-reply postage) and an instructional page presenting the tasks required in the study, frequently asked questions and answers (both groups) and username/password instruction for using the study Web portal (intervention group only).

Participant Incentives:

Since financial incentives itself can improve patients' adherence [Giuffrida, 2003], either all participants (including controls) or none of them should receive incentives.

Participants recruited at the pharmacy and fitness center sites did not receive financial incentives. Participants recruited at the Atlanta headquarters received a \$10 gift-card when they returned their signed consent forms at the recruitment table (n=40), or a few weeks later if they had returned their registration using the pre-paid return envelope (n=9).

Pharmacy Materials:

The following material will be provided to the pharmacy participating to this research study:

- Study manual
- Patients study material and consent letters.
- Reminder magnets about the targeted study population to remind technicians and pharmacists.
- Announcement cards to staple to prepared bags containing refilled medications to be picked up by the patients.
- Poster signs announcing the study at the pharmacy.

Baseline Questionnaire

The first questionnaire (see Appendix J) included background information, questions about previous use and experience with Internet for seeking health information or in general,

and eHealth self-efficacy. Demographic variables will include gender, age, race/ethnicity, education, health insurance, drug coverage and household income. Contact information will also be collected in order to make further follow up communications.

Final Questionnaire

After 2 months, participants received an email invitation to complete the follow up survey. The online questionnaire was developed using phpSurvey freeware (phpSurvey 2.0-alpha, 2003) with PostGreSQL databases (Suryajaya, 2003).

The survey includes questions assessing drug and disease knowledge, lifestyle change awareness, perceived learning, Internet seeking behaviors, communication with pharmacist, communication with physician, modification in treatment recommendation.

Measures

eHealth Self-efficacy:

An eHealth self-efficacy scale was adapted based on Internet and computer self-efficacy scales. The measure was tested for its internal reliability and validity. Based on the Social Cognitive Theory, self-efficacy was tested for its nomological validity. This is the evaluation of the relationship with other constructs. (See Chapter 5)

Medication Adherence:

A self-reported measure of medication adherence named *Hill-Bone Compliance scale* was used in this study (Kim, Hill, Bone, 1999). This scale was adapted to be specific to hypertension, high cholesterol or diabetes treatment. A total summated score (range 8-32) of the eight 4-point Likert-type items was computed for each respondent as an estimate of their medication adherence. The scale was chosen due to its good internal reliability with Chronbach's alphas of 0.85 (study one), and 0.74 (study two). The instrument showed good

support for validity with assessment of construct validity with high blood pressure metrics, appointment taking and salt consumption. The total scale had 14 items, but two sub-scales assessing sodium intake and appointment adherence were not used in the current study.

Other instruments such as the Brief Medication Questionnaire (BMQ) which presented limited evidence of validity to predict medication adherence [Svarstad et al., 1999] was not chosen due a lack of reliability and validity (Cook, 2002; Choo et al., 1999).

Knowledge Assessment:

An instrument was developed to assess this construct based on existing instruments. The knowledge questionnaire covered four domains: (1) the disease and its treatment, (2) the cardiovascular risk factors, (3) the prevention of complications, (4) physical activity and diet. Item generation will be based on similar knowledge measures developed for assessing knowledge of heart defects, hypertension and their treatments [Ceta and Warns 1995; Warns 1995; Moons et al. 2001; Duff, Simpson et al., 2000; Cuspidi C, et al., 2001].

Hypertension knowledge was previously assessed using a pre-tested questionnaire of 5 questions scored with two points for each correct answer for a total of 10 points [Duff, Simpson et al., 2000]. Bobb-Liverpool et al., (2002) used the adapted instrument in 80 women with hypertension. They found no influence of knowledge score on medication adherence, diet or exercise [Bobb-Liverpool, Duff and Bailey, 2002]. The author (EMW Duff) explained that the instrument is “education level and culturally specific” [Personal communication, July 14th, 2003] Consoli et al. (2002) evaluated which factors predicted patients’ opinion on the required length of treatment. The self-administered questionnaire used in the FRACTION study had 27 items (short open-ended, multiple choices or Likert-type answers). Naslund et al. (1996) measured the health knowledge construct using a matrix of seven health problems (e.g. heart disease, high blood pressure, and elevated blood lipids) and nine potentially related factors (e.g. smoking, alcohol, physical exercise, salt, animal fat, dietary fiber). They computed the score for

cardiovascular health knowledge by summing the correct answers for which factors are associated to heart disease, high blood pressure, and high blood lipids. They found that poor knowledge of CHD risk factors predicted poor adherence with increased intake of fiber. [Naslund et al., 1996]

Three parallel questionnaires were created to assess disease specific (diabetes, high cholesterol and hypertension) and general cardiovascular knowledge. The questionnaires were pre-tested with students in pharmacy or other departments.

During pre-testing, knowledge means were significantly different between the groups of students ($p < 0.001$). Items with higher item difficulty score (~ 1.0) were removed, as they would not help differentiating respondents.

4.4. Study Web Portal

4.4.1. Development of the Web Portal

The study Web site presents a collection of selected links to existing Web sites provided by U.S. national or governmental groups, general health commercial Web sites, or drug-specific Web sites provided by pharmaceutical companies (e.g. atorvastatin on HealthAtoZ.com URL: <http://www.healthatoz.com/healthatoz/Atoz/drugdb/drugLeaflet.jsp?id=6419> [Accessed July 25, 2004], Lipitor® URL: <http://www.lipitor.com/> [Accessed July 25, 2004]). The study Web directory was created based on simulated searches consumers would perform when seeking drug-related Web sites. The Appendix Q presents a sample of screenshots of the Web portal.

Phase A: Retrieval of Web Sites Providing Prescription Drug Information.

The search of Web sites intended to simulate consumers seeking drug-related Web sites in a general way using keywords for prescription drug information in English. Some governmental agencies and the media provide ethnic and language specific health-related

content online, but were not included in the Web portal, as they did not meet the inclusion criteria.¹

It was estimated unlikely that drug-specific Web sites would have been retrieved with the search strategy described above. Therefore, in a second step, brand medication specific Web sites supported by pharmaceutical companies was added to the Web portal.

Web Site Selection Criteria:

Inclusion criteria:

Web sites were included as sources of information if they met the following characteristics:

- The Web site has a privacy policy is directly linked from the home page

AND

- The Web site has a search engine, a link for drug information, or directory of medication specific pages

OR

- The Web site is retrieved directly by searching on the primary Web site or is linked as a source for drug information

OR

- The Web site is product specific (brand) provided by the manufacturer or is the manufacturer's Web site (U.S.A.).

Exclusion criteria:

Web sites with the following characteristics were not included:

- The Web site has no privacy policy.
- The Web site requires a log-in step, even if free of charge
- The Web site uses pop-up window advertising or surveys
- The Web site is only selling prescription drugs

¹ CDC.gov in Spanish and MedLinePlus section for African American, CNN en español (health).

- The Web site is an official or unofficial e-pharmacy
- The Web site is provided by a pharmacy chain or an individual pharmacy
- The Web site presents pornographic content, irrelevant advertising or suspicious activities
- The Web site is only a Web directory of external links
- The Web site has a searchable tool for medication information that links to an outside Web site (as per inclusion criteria, that “secondary retrieved Web site” can be considered for inclusion).

Search Strategy for Web Sites:

Separate searches were done with the key words “medication”, “medicine”, “prescription”, and “prescription drug information”. The following search engines were used: AOL.com, AltaVista.com, Google.com, MSN.com and Yahoo.com (Google).

The search engines were selected based on two criteria: the popularity (visitors/day) and the frequency of use (searches/day). The most popular services were AOL, MSN-sites, Yahoo! Sites and Google (December 2001). The most frequently used services were Google and Alta Vista.

Phase B: Retrieval of Drug-specific Web Pages from the Selected Web Sites

This last phase consisted of the creation of the Web portal to guide users to existing sources of information on prescription drugs for the treatment of hypertension, dyslipidemia, diabetes, and rheumatoid arthritis.

Search strategy for the selection of Web pages:

Each of the selected Web site was used to retrieve the links to pages presenting information about each study drug. Searches were performed with the generic or trade name of the drug or using the navigation options available on the Web site.

For Web sites provided by the manufacturers, either the home page of the drug specific Web site were used as a direct link. If a product specific Web site was not available, the manufacturer's site was navigated to locate a Web page presenting the product to consumers (US residents). As a second choice, a link directly to the patient package insert as a portable document format (PDF) file was used if this was the only information provided by the manufacturer about the product.

Phase C: Conception of the Study Web Portal

Web site Hierarchy

The hierarchy was as follow:

- 1.0 Therapeutic indication (high blood pressure, High cholesterol, diabetes and rheumatoid arthritis treatments)
 - 1.1. List by generic and brand names for the therapeutic indication, guiding to a medication-specific page suggesting links to sources of information.
 - List of links to various generic drug information Web pages
 - Links to a brand-specific or manufacturer's Web sites.
- 2.0 Alphabetical listing of drugs by generic and brand names
 - 2.1. List by generic and brand names for all 4 therapeutic indications. A brand and its generic name linked both to the same page. This medication-specific page then listed a suggestion of sources about the medication as described in 1.1.

The Web site was accessible using the URL <http://www.RxLinx.org>, which redirected users to the University of Georgia's server at <http://www.RxLinx.uga.edu>.

CHAPTER 5

AN ADAPTED MEASURE OF EHEALTH SELF-EFFICACY¹

¹ Provost M., Perri III, M. To be submitted to *Computers in Human Behavior*.

Abstract

This paper discusses the initial psychometric evaluation of a scale to measure the construct of eHealth self-efficacy. EHealth self-efficacy is defined as an individual's perception of his or her ability to use the Internet to find health resources. Using 132 employees at a large corporate headquarters (Atlanta, GA, USA), a 6-item scale was evaluated for its reliability and construct validity. The relationships between (a) eHealth self-efficacy, and (b) browsing self-efficacy, Internet use, email use, eHealth use, computer anxiety, perceived impact of using eHealth information, and personal eHealth information outcomes expectancy, were found significant. Higher levels of eHealth Self-efficacy are significantly associated with Web browsing self-efficacy ($r = 0.336$, $p < 0.01$), Personal eHealth Information Outcomes Expectancy ($r = 0.343$, $p < 0.01$), and Perceived Impact of using the EHealth information ($r = 0.323$, $p < 0.01$). People with higher self-efficacy in seeking health information on the Web are more likely to access health information online and are more likely to perceive the benefits of the use of eHealth. The existence of instruments with evidence of reliability and validity in assessing constructs such as eHealth self-efficacy carries implications for researchers in the field of eHealth where there are scant resources for measuring eHealth behaviors.

Keywords: eHealth, Internet, health behavior, measurement, test reliability, test validity.

Introduction

It is estimated that up to 73 million Americans (40-62% adults who are online) have used the Internet to seek health information (Horrigan, & Rainie, 2002; Baker, Wagner, Singer & Bundorf, 2003). This use of information affects even more individuals, labeled “indirect users” of eHealth, when a friend or family member seeking eHealth information shares it (Horrigan & Rainie, 2002; Taylor & Leitman, 2002; Fleisher, Bass, Rusek & McKeown-Conn, 2002). EHealth includes use of the Internet or other electronic media by the public, health workers, and others to access health related information, services, and support (Eysenbach, 2001; Wyatt & Liu, 2002; Gustafson & Wyatt, 2004). Although a digital divide still exists in developed countries, it is expected that access to the Internet will increase and the costs associated with going on-line will decrease as a result of governmental and private efforts. But, even with increased access we will still need to ascertain how people with Internet access may benefit from the use of health information found online. Further, why do some Internet users seek health information online while other users do not. Research is needed to better understand the behavior of people who use eHealth information (Eysenbach, 2002; Jadad & Delamothe, 2004). In particular, there is a need for validated and reliable instruments specific to eHealth.

Understanding the use of the Internet by individuals for health-related purposes is critical to our understanding of its potential impact on public health. One of the goals in eHealth research is to understand the factors that influence utilization of EHealth resources. Based on the Social Cognitive Theory, people regulate their behavior through internal standards and self-evaluative reactions to their own behavior. (Bandura, 1986) Among several dimensions, two sets of expectations are major cognitive forces guiding behaviors: self-efficacy and outcomes expectation.

The self-efficacy construct has been employed in several specific health areas: self-efficacy in coping with cancer (Fleisher et al., 2002), medication adherence self-efficacy (Cook, 2002), and smoking cessation self-efficacy (DiClemente, 1981). The self-efficacy construct is

also a useful base in measuring self-perception regarding information technology applications (Torkzadeh & Van Dyke, 2001): Computer self-efficacy (Compeau & Higgins, 1995), and Internet self-efficacy (Torkzadeh & Van Dyke, 2001; Eastin & LaRose, 2000). Internet self-efficacy is “the belief in one’s capabilities to organize and execute courses of Internet actions required to produce given attainments” (Bandura, 1986; Eastin & LaRose, 2000). Bandura suggested that self-efficacy should be tailored to the specific domain of interest in order to maximize predictability (Bandura, 1986).

To address specific needs in understanding behaviors of Internet users seeking health information, self-efficacy will be tailored to that specific domain of interest. EHealth Self-Efficacy represents an individual’s perception of his or her ability to use the Internet to find health resources. As stated by Bandura, self-efficacy “is concerned not with the skills one has but with the judgments of what one can do with whatever skills one possesses”. (Bandura, 1986, p.391) Thus, the tasks should not reflect simple component skills: for example, deleting spam medication advertising from your mailbox, typing medical terms for a search engine query, or accessing your medical records on your provider’s web site.

Outcomes expectation for performing a behavior is one of the major driving cognitive forces explaining behaviors (Bandura, 1986). Individuals are more likely to undertake behaviors they believe have favorable consequences than behaviors not perceived as having positive outcomes. Although people have access to the Internet, they may not seek health information if they do not perceive the benefits of performing this information seeking behavior.

The objective of the study was to evaluate a measure of health specific Internet self-efficacy, and assess its reliability and construct validity within the theoretical framework of the Social Cognitive Theory.

Methods

Participants

Two samples of respondents were used in this study to evaluate the eHealth self-efficacy scale's basic psychometrics properties. The project was approved by the Institutional Review Board of the University of Georgia, and was compliant with the Health Information Portability and Accountability Act of 1996 (HIPAA).

A main sample was composed of participants who were recruited among employees of a multinational corporate headquarters in Atlanta, Georgia, with more than 5000 employees at this site. Two hundred and fifty volunteers were recruited on site by the principal investigator. Participants did not receive any incentives. Each participant voluntarily provided his or her email addresses to receive the link to the online survey. Six email addresses were not usable. Of the 244 volunteers, 132 respondents provided usable survey data (response rate of 53%). A second sample of 81 respondents, recruited from community pharmacies (3 chain stores, 5 independents), a senior community group, a Cardiac Rehabilitation and Adult Fitness Center, and a large multinational corporate headquarters, was also administered a paper and pencil version of the eHealth self-efficacy scale.

Measures and Procedure

A 43-item online questionnaire was used in this study. The instrument presented three sections: 1) Internet use in general and for health-related purposes, 2) demographics, and 3) health status and satisfaction with health information and care.

A literature review was performed for a domain assessment of items measuring computer and Internet self-efficacy in order to adapt a scale specifically to the domain of EHealth information seeking (Table 5. 1). The "eHealth Self-efficacy" instrument was created based on prior work of Eastin & LaRose (2000) and Compeau & Higgins (1995). These instruments measured Internet Self-efficacy (8 items; $\alpha = 0.93$) and Computer Self-efficacy (10

items; internal consistency reliability of 0.95), respectively. Both instruments were supported by evidence of construct validity, discriminant validity and related to other constructs as expected (nomological validity) (Table 5. 1). (Eastin & LaRose, 2000; Compeau & Higgins, 1995). Computer use differs from Internet use, so each item was assessed for face validity related to the domain of interest, eHealth information seeking. Wording of the Computer Self-efficacy items was modified to reflect use of a Web site to seek health information. Four items from the Computer Self-efficacy were adapted to replace “I could complete a job using the software” with wordings related to seeking health information or using health Web sites. Two other items were created based on items from these scales that address the “gathering of information” and the “use of manual”. Thus, the items related to search engine usage and Frequently Ask Question (FAQ) page were added. The elements of task difficulty from Compeau and Higgins (1995) was applied to the scale (different levels of support in each item) that capture differences in magnitude, which is one of the dimensions of the self-efficacy judgment (Bandura, 1986). This approach has been taken by others to measure attendance self-efficacy and smoking cessation self-efficacy (Compeau & Higgins, 1995; Frayne & Latham, 1987; Condiotte & Lichenstein, 1981; DiClemente, 1981)

Based on these existing scales and on the definition of eHealth self-efficacy, the adapted scale relates specifically to health information. The various levels of support presented by Compeau and Higgins (1995) in their instrument were used as a basis for item development. Further, redundant items were collapsed into a single item. Pre-testing lead to further removal of an item that was confusing to the respondents. The final eHealth self-efficacy instrument consisted of 6 items. A 5-point Likert-type scale was used to assess the participant's confidence that they could seek health resources on the Web. The use of the Likert-type scale offers an acceptable alternative to measure self-efficacy magnitude and strength compared to the “traditional method” (Maurer & Pierce, 1998; Maurer & Andrews, 2000). The “traditional method” refers to the typical format to assess self-efficacy magnitude and strength. In this

format, the participants first respond yes or no to a question of whether or not he or she will be able to perform a specific task at a certain level (assessing magnitude), then give his or her percent of confidence in that answer (assessing strength). (Bandura, 1986; Maurer & Pierce, 1998) For consistency in response scales in this questionnaire, the Likert-type scale was chosen as an acceptable alternative to measure self-efficacy. The responses ranged from 1 (strongly disagree) to 5 (strongly agree), with each response labeled and 3 as “neither agree or disagree”. Summated total score can range from 6 to 30.

The “Personal Health Information Outcomes Expectancy” (PIOexp) was based on Eastin and LaRose’s (2000) Personal Information Outcome Expectancy scale (6 items; $\alpha = 0.83$) that assessed the likelihood of finding immediate information on the Internet. The PIOexp modified items reflected specifically the health domain in a verbatim manner (for example, “Get [health] information I can trust”), or was modified to reflect health content. For example “Find current information like time, weather, stock prices and sport scores” was modified to “Find current information like health news, new drug discoveries, clinical trials, and epidemic outbreaks”. This scale has a 5-point Likert-type responses (1= Very unlikely, 5 = Very likely).

To measure a general Internet self-efficacy one of the 3 items (highest loading) was selected from the “Browsing” factor ($\alpha = 0.93$) of Torkzadeh and Dyke’s (2001) 17-item Internet Self-efficacy ($\alpha = 0.96$). One item was considered representative of the construct. As shown with the high internal reliability alpha value, each item is representative of the entire scale. In fact, the face validity of “I feel confident surfing the World Wide Web (WWW)” is similar to “I feel confident browsing the World Wide Web (WWW)”. A 5-point Likert scale was used as with the previously described instruments.

The Computer Anxiety Scale had 3 items based on Barbeite and Weiss’s “Anxiety using computer” subscale ($\alpha = 0.76$) to which an item with a lower loading on the factor was removed. A 5-point Likert scale was also used (1= strongly disagree, 5 = strongly agree).

Total Internet Use consisted of the sum of the responses to two items assessing the number of hours the participants use the Internet for emailing and the number of hours per week the participants are on the Internet for purposes other than sending emails. A single item assessed the frequency of using the Internet for health information (1 = never, 2 = once or twice a year, 3 = every few months, 4 = about once a month, 5= once a week or more).

Content validation of the “eHealth Self-efficacy” scale was performed by a panel of 10 senior graduate students and Faculty members from the Colleges of Education and Pharmacy. The “Personal Information Outcome Expectancy in Health” was adapted to the health care context based on an existing general scale, while the “Perceived Impact of Using Health Web” was composed of items created by the authors and items adapted from previous studies (Fleisher et al., 2002).

The online questionnaire was developed using phpSurvey freeware (phpSurvey 2.0-alpha, 2003) with PostgreSQL databases (Suryajaya, 2003). The phpSurvey option of anonymizing individual data was selected as well as the ability for the respondent to save their answers and complete the questionnaire at a later point. Modified scales were pre-tested with staff of the College of Pharmacy (phpSurvey n=15 and paper format n=15).

Data collection of the main sample was performed between May 7 and May 24, 2004. Each participant of the main sample received an email invitation to complete the questionnaire using an individualized access link and a link to a Web page with login and password access. Two email reminders, including links to the survey, were sent to the non-respondents during the data collection period. Measurement of eHealth Self-efficacy in the second sample was done using a paper and pencil format.

Raw data was automatically collected when participants submitted their answers online. Data extraction was possible using the administrative Web interface of phpSurvey. Tables were retrieved with structured query language (SQL) queries.

Analyses

All analyses were performed using SPSS 12.0 for Windows (Scientific Software, 2003). The item analyses for the scales used in this study included a review of the frequency distribution of each item, correlation matrices, corrected item-total correlations, and Chronbach's alpha if an item is deleted. A measure of reliability for each scale was done using Chronbach's alpha. Convergent and discriminant construct validity of the "eHealth Self-efficacy" was assessed using a correlation matrix (Pearson correlation, $\alpha = 0.05$). Exploratory factor analyses (Principal Component analysis and Varimax rotation) were conducted to determine the underlying factor structure of the adapted scale. The number of factors in each scale was determined by scree plot analyses and based on the eigenvalues greater than 1.

Results

1. Participants

The sample consisted of 50% males (2 missing responses) mostly Caucasian (63.6% white; 25.8% African American). The age of the participants ranged from 21 to 65 year old (median and mean = 38.0, S.D.=9.2). The respondents were well educated: 76.2% were college graduates or post-graduates and an additional 20.6% had some college education. Respondents in this sample appeared healthy (94.5% reported at least a good health status; 41.9% taking a prescribed medication).

The second sample was composed of 81 respondents (51 men (63.0%) and 30 women). The age of the participants ranged from 32 to 87 year old (Median = 54.0, Mean = 56.1, S.D.=14.1). The respondents were well educated: 71.6% were college graduates or post-graduates and an additional 21.3% had some college education. They were experienced with the Internet in general.

2. Item Analysis and Reliability

2.1 eHealth Self-efficacy Scale

Item frequency distribution indicated potential to differentiate respondents using this scale. Responses were distributed over the range of all Likert-type categories. All skewness values were less than 1.0; therefore, they were not considered problematic. Two items (“finding by myself” and “using a general search engine”) had high Kurtosis values indicating a leptokurtic (highly peaked) distribution that departs from normality. This can reduce the discriminating power of those items. In fact, 87.5% agree or strongly agree with the statement “I feel confident finding health resources on the Web by myself”, and 85.2% agree or strongly agree to “I feel confident that I could find health resources on the Web using a general search engine”. The general self-efficacy item (Torkzadeh & Dyke, 2001) also indicated problematic skewness and very high Kurtosis.

If all items represent the same construct, each item should be correlated with the total score corrected by removing the item’s own contribution. As shown in Table 5.2, the corrected item-total correlations were relatively low (ranging from 0.25 to 0.41).

Based on the main sample, Chronbach’s alpha for the eHealth Self-efficacy scale was 0.597. The low reliability may be partly due to a small number of items (Cortina, 1993). Also, lack of response variability across respondents can result in low internal consistency (Crocker & Algina, 1986). However, each item contributed to the internal consistency of the scale. No item reduced the reliability since there was no increase in alpha when each individual item was deleted (Table 5. 2). Each individual subscales of the eHealth self-efficacy scale showed better, but still low, reliability ($\alpha = 0.66-0.68$). These results are within the range for acceptable reliability being larger than 0.50 (Helmstadter, 1966) and near 0.70 (Nunnally, 1994). The reliability results were improved in the second sample with a Chronbach’s alpha of 0.724.

2.2. Other scales

The “Perceived Impact of Using Health Web” scale was built of work from Fleisher et al. (2002), and the “Personal Health Information Outcomes Expectancy” scale (Eastin & LaRose, 2000) adapted for the health context showed acceptable or good reliability with alphas of 0.651 and 0.919, respectively (Helmstadter, 1964; Nunnally, 1994). The reduced Computer Anxiety Scale ($\alpha = 0.939$) showed an increased reliability compared to the original validation study of the 4-item scale ($\alpha = 0.76$) (Barbeite & Weiss, 2004).

3. Factor Analysis for the eHealth Self-Efficacy

To evaluate the underlying structure of the eHealth Self-efficacy construct, principal components as a mean of extraction with Varimax rotation was employed. The ratio of sample size to items (21:1) was greater than the accepted standard (10:1). The scree plot analysis indicated a 3-factor solution. Looking at the eigenvalues, the third component extracted has an eigenvalue of 0.935 and explained an additional 15.58% of variance. The 3-factor solution was investigated but lead to high cross-loadings (0.36 and 0.52) on the two other factors. Therefore, the strict cut-off based on eigenvalue greater than 1.0 was used.

The two factors (3 items in each) explained 62.7% of the variance. The item loadings greater than 0.4 are highlighted in Table 5.3. All items except one highly and clearly loaded on one of the factors (range 0.709 to 0.886). Only one of the items showed a lower primary loading on one factor, though higher than 0.50 (“as long as I have plenty of time to search”). None of the items had a cross-loading greater than 0.30, which indicates an unambiguous structure where each item strongly associates with only one factor.

The naming of the underlying dimensions of the self-efficacy scale was based on the social cognitive theory (Bandura, 1987). People judge their personal capabilities through cognitive appraisal of relevant information. Many factors other than capability influence the appraisal of self-efficacy (Bandura, 1987). How people alter their perceived efficacy at various

levels will depend upon, among other factors, the difficulty of the task, the amount of external aid they receive, the circumstances under which they perform, and the temporal pattern of their successes and failure (Bandura, 1987). The items in the first factor reflect different levels of external aid (site design or someone to contact) or performing in an unknown environment that is not part of the person's past experiences (new site). Therefore, this factor was named "External support". The second factor corresponds to a more internal assessment of self-efficacy as its items indicate circumstances where the user has greater control over the tasks and decisions. The second factor was labeled "Self-control".

Coefficient alpha reliability scores were 0.662 and 0.677 for External support and Self-control, respectively. Table 5.3 also provides a factor correlation matrix, and means and standard deviations for the two factors.

4. Construct Validity for the eHealth Self-Efficacy

The correlation matrix was analyzed for convergent and discriminant validity of the new measure. EHealth self-efficacy was expected to have a moderate to high correlation with the existing measure of generic Web browsing self-efficacy (convergent validity) and to have a moderate negative correlation with a measure of anxiety toward using a computer (discriminant). Convergent validity was also assessed by looking at the relationship of the self-efficacy measure with indicators of Internet use in general or for health purposes. A stronger relationship was expected with health specific Internet use than general Internet use. Table 5.4 shows the inter-correlations among the measures.

The eHealth self-efficacy scale significantly correlated in the expected directions and levels with the generic web self-efficacy, anxiety using a computer, the personal health information outcomes expectancy, and perceived impact of using the Web for health information. This provides support to the validity of the construct of eHealth Self-efficacy, which correlates with other constructs and measures as expected in the theoretical framework.

Higher levels of eHealth Self-efficacy are significantly associated with Web browsing self-efficacy ($r = 0.336, p < 0.01$), Personal Health Information Outcomes Expectancy ($r = 0.343, p < 0.01$), and Perceived Impact of using the EHealth information ($r = 0.323, p < 0.01$). People with higher self-efficacy in seeking health information on the Web are more likely to expect accessing a wealth of health information online (PIO-health measure) and are more likely to perceive the benefits of the use of health Web on their self-healthcare behaviors and attitudes (Perceived Impact measure). The results are consistent with previous work that showed Internet self-efficacy is associated with personal information outcome expectancy (Eastin & LaRose, 2000)

Higher levels of EHealth Self-efficacy are significantly related to lower levels of anxiety toward using a computer ($r = -0.238, < 0.01$), though more weakly than general Web browsing correlated with the levels of anxiety ($r = -0.470, p < 0.01$). This may be explained by the generality of the tasks mentioned in the anxiety measure and the browsing self-efficacy, which lead to skewed responses.

The specificity of the eHealth self-efficacy is also observed in the results about the relationships with Internet use in general or for health purposes. Higher levels of EHealth self-efficacy are significantly associated with the frequency of health web use ($r = 0.21, p < 0.05$), but not associated with the level of Internet use in general. As expected, the general Web browsing self-efficacy did not correlate with the frequency of health Web use.

Discussion

This study examined the relationships between eHealth self-efficacy and other constructs within the framework of the Social Cognitive Theory. The development of these instruments, evaluated for their basic psychometrics properties, is responding to a need in eHealth research. As expected there were significant relationships between eHealth self-efficacy and Personal Health Information Expectancy, Perceived Impact of using eHealth,

anxiety using computer (negatively related), and the level of eHealth use. Therefore, these are all constructs to be considered when investigating the eHealth behavior of seeking health information on the Internet.

The self-efficacy construct has been evaluated in eHealth studies comparing groups of Internet users or non-users (Fleisher et al., 2002; Eysenbach, 2003; Etter & Perneger, 2001). Clarifications may be appreciated to address the purpose of the eHealth self-efficacy compared to past assessment of self-efficacy in eHealth studies. Most of these scales are disease specific, for example, self-efficacy coping with cancer (Fleisher et al., 2002), and do not assess a person's Internet self-efficacy specific to health seeking behaviors. Assessing self-efficacy with a health behavior among Internet users and non-users, is a different construct than eHealth self-efficacy, which is the individual's perception of his or her ability to use the Internet to find health information.

The relatively low reliability ($\alpha = 0.597$) of the eHealth self-efficacy scale in the main sample may have been partially due to the lack of response variability across respondents (Crocker and Algina, 1986). The main sample used in this study was Internet savvy and was healthy, young and educated. As observed in the second sample, an increased reliability was seen in the more heterogeneous sample having various levels of eHealth self-efficacy. This result is defined as an adequate reliability, even when considering a more conservative lower limit (Nunnally, 1994). Since the number of items also affects reliability results, a larger number of items would increase Chronbach's alpha.

Responses to some of the items on the eHealth self-efficacy and the general Web browsing self-efficacy were skewed. This may be explained by a greater experience of the respondents in our samples in performing basic online activities; therefore, being self-efficacious in their ability to do the job. The different distributions of the item responses and the lack of variance in some items may also explain part of reasons for the relatively low corrected item-total correlations.

Measuring the frequency of eHealth use may contribute to explain eHealth seeking behavior more than the level of Internet usage would contribute. There was no significant relationship between the levels of weekly Internet use (excluding emailing) and the perceived impact of eHealth use and the personal health information outcomes expectancies. This means that although people may be using the Internet a lot during the week, they may not turn to the Web to get eHealth information if they do not perceive this behavior as beneficial. A different research design would be necessary to propose further explanations for these results.

This study has various implications for increasing knowledge on the behavior of people using the Internet to seek health information. Measurements of eHealth self-efficacy can be included in research projects. Also, addressing self-efficacy can help to better understand e-patients behaviors in a Web-based education programs can; this can help clinicians to adapt training based on the individual's eHealth self-efficacy. Another aspect of this work relates to scale development and measurement field that shows a gap in knowledge but opportunities to seize in the domain of eHealth. The present eHealth self-efficacy can be further evaluated, built upon, or used in the assessment of other instruments in eHealth.

Future studies can include measurements of eHealth self-efficacy and health information outcomes expectancy. A potential use can also be found by assessing self-efficacy as part of the evaluation of training programs to help people develop skills to use the Internet to gather health information.

People who have a strong sense of efficacy make more vigorous and persistent efforts than people with self-doubts about their capabilities (Bandura, 1986). The importance of self-efficacy in seeking health information may be determinant in the efforts and persistence people can take for finding relevant and beneficial information. Although a few rigorous studies have evaluated the benefits from eHealth use, there are indications from e-patients who self-reported that the use of eHealth can improve the way they take care of themselves. However, e-patients with lower eHealth self-efficacy may stop their search activity even before reaching helpful

information. An individual having lower self-efficacy in seeking eHealth information may give up when he or she retrieves irrelevant or untrustworthy Web pages, for example, finding too much advertised and doubtful prescription drug Web pages. People facing a new diagnosis turn to the Web to gather information. Self-efficacy may play a role when newly diagnosed patients use search engines with unfamiliar medical terms or medication where, again, persistence in their effort may be necessary to find relevant eHealth information intended for patients.

There is a significant relationship between eHealth self-efficacy and the frequency of using the Web for health purposes, but the relationship is not observed with the level of Internet use in general (number of hours online, or emailing). This result reinforces the need for researchers in eHealth to be specific when assessing the level of use in Web seeking behavior. Based on these results, researchers should not assume that people using the Internet more often would perceive themselves as more confident in their ability of seeking health information on the Web.

Limitations

The low internal consistency of the adapted scale is problematic. However, the reliability estimates would increase with an greater number of scale items, with a more inclusive list of items from the domain of interest. More detailed items could be added to reflect various health topics to expand the generalizability of the self-efficacy. This eHealth self-efficacy instrument does not capture the generalizability dimension of the self-efficacy judgement. For example, self-efficacy in seeking information related to medications for cancer treatment may differ from finding information about healthy lifestyle. More difficult tasks could be addressed in a additional items related to other health aspects such as finding the best price for a medication in a reliable online pharmacy”.

Limitations also exist related to the convenient sample used in this study that may not be representative of the population in general that includes non-users of the Internet. Internet

surveys present challenges due to the unreliability of the systems, and the instrumentation bias can be introduced related to the surveying methods. Sample selection bias also exists since people used to answer online surveys may have been more likely to answer this survey as well. The technology may have also influenced the response rate since some volunteers may not even have received the email about the survey. Therefore, the response rate may be underestimated.

Future research and Implications

Research is needed to evaluate how eHealth self-efficacy and outcomes expectancy predicts the use of the Internet for health purposes. One may hypothesize that outcomes expectancy may not add much to the prediction of eHealth information seeking. This can be the case when expected outcome is highly dependent on self-efficacy judgment as has been shown in several behaviors. (Bandura, 1986)

Further study is encouraged to generate greater support for validity, reliability and generalizability in different samples or population (e.g. non-Internet users), for example, elder Internet users taking medication for certain chronic diseases. As gender differences were reported in computer-related tasks and rating of self-efficacy (Torkzadeh, Pflughoeft & Hall, 1999; Torkzadeh & Van Dyke, 2002; Schumacher & Morahan-Martin, 2001; Carlson & Grabowski, 1992; Jorde-Bloom, 1988; Miura, 1987; Hawkins, 1985), and more women use the Internet for eHealth seeking than men, research may be needed to investigate if there exists a difference in eHealth self-efficacy among males and females. More research can also be done to evaluate the causal relationships of the different constructs of the Social Cognitive Theory applied to the use of the Internet by people seeking health information.

Finally, future research should include eHealth self-efficacy measures. This important theoretical construct can help researchers understand why individuals seek health information online, use Web site tools in their health decision-making process, persist in their quest using

search engines, and eventually succeed in retrieving trustworthy and good quality of eHealth information.

Conclusions

The eHealth Self-efficacy scale has shown moderate internal reliability, and is supported by evidence of construct, convergent and discriminant validity. Based on the Social Cognitive Theory, the eHealth self-efficacy is significantly associated with frequency of use of health information, personal health information outcomes expectancy, perceived impact of health web use. However, there is no association between self-efficacy of seeking health information and the level of use of the Internet in general.

**Supplement: Instruments assessing eHealth Self-efficacy, Personal Health Information Outcomes,
Perceived Impact of Using eHealth [Original format was Web-based]**

<i>eHealth Self-efficacy</i>^{* 1}	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I feel confident using a new health Web site I have never used before.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel confident finding health resources on the Web if the Web site had a Frequently Asked Questions (FAQ) section.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel confident that I could find health resources on the Web if I had someone to call or email if I got stuck.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel confident finding health resources on the Web by myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel confident finding health resources on the Web as long as I have plenty of time to search.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel confident that I could find health resources on the Web using a general search engine (ex.: Google, AOL, Yahoo).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

(Supplement cont'd)

<i>Personal Health Information Outcomes</i> ^{*2}	Very unlikely	Unlikely	Neutral	Likely	Very likely
Find current information like health news, new drug discoveries, clinical trials, and epidemic outbreaks.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get information about medications, devices and health services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get immediate knowledge of big health news events.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get health and drug information you can trust.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Find health information that is new to you.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Learn about controversial health information.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Learn about healthy lifestyles (including nutrition, exercise, prevention)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

(Supplement cont'd)

Perceived Impact of Using Health Web^{*1}

Using the Web to find health information...	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
...I feel I have more power to make decisions about my health.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...can help me talk with my doctor about my health.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I feel that getting the information is overwhelming.**	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...makes me confused as to the right course of treatment for my disease.**	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<i>...makes me aware of conflicting medical information about my disease and its treatment.[removed item]</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...helps me take better care of my own health.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

¹ Item question: How much do you agree or disagree with the following statements?

² Item question: How likely or unlikely is it for you to use the Web to do each of the following task?

*Titles of the scales were not mentioned in the questionnaire used by respondents.

**Negatively worded item.

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Table 5.1 Computer and Internet Self-efficacy Instruments

Instrument	Sample	Subscale/Factor (Number of items)	Mean scores (SD)	Reliability	Validity
<i>Computer Self-efficacy Scale</i> Murphy, Coover & Owen (1989)	414 computer skills students	Beginning skills (4) Advance skills (4)	NA NA	$\alpha=0.97$ $\alpha=0.96$	NA
<i>Computer Self-efficacy Scale</i> Barbeite & Weiss (2004)	227 members of an international online research panel	Beginning skills (4) Advance skills (4)	4.73 (0.54) 3.14 (1.10)	$\alpha=0.83$ $\alpha=0.85$	Relationship with computer and Internet use. Negatively related to anxiety using computers.
<i>Internet Self-efficacy</i> Eastin & LaRose (2000)	171 undergraduate students	Single factor (8)	36.11 (11.76)	$\alpha=0.93$	Prior Internet experience, outcome expectancies and Internet use were significantly positively related. Internet stress and disparagement were negatively related.

(Table 5. 1 continues on the following page)

(Table 5. 1 cont'd)

<i>Internet Self-efficacy</i> Tsai & Tsai (2003)	73 college freshmen	No factor analysis (6)	16.85 (3.66)	$\alpha=0.80$	NA
<i>Internet Self-efficacy</i> Torkzadeh & Van Dyke (2001)	277 students in information system course	Browsing (3) Encryption/decryptio n (6) System manipulation (8)	NA	$\alpha=0.93$ $\alpha=0.98$ $\alpha=0.94$	Limited content validity
<i>Computer Self-efficacy</i> Compeau & Higgins (1995)	1,020 subscribers to a business periodical	Single factor (10)	NA	$\alpha=0.95$	Construct validity, discriminant validity, nomological validity. Positively related to outcomes expectation, affects and use. Negatively related to anxiety.

Table 5.2 Scale and Item statistics for the Personal Health Information Outcomes Expectancy, Perceived Impact, and the eHealth Self-efficacy Scales

Item description	M	(SD)	Corrected item-total correlation ^c	Alpha if item deleted ^c
<i>eHealth Self-efficacy ($\alpha = 0.597$) $n=125$</i>				
Factor 1: External support ($\alpha = 0.662$)				
I feel confident using a new health Web site I have never used before.	3.21	0.845	0.411	0.519
I feel confident finding health resources on the Web if the Web site had a Frequently Asked Questions (FAQ) section.	3.41	0.774	0.356	0.544
I feel confident that I could find health resources on the Web if I had someone to call or email if I got stuck.	3.44	0.979	0.251	0.594
Factor 2: Self –control ($\alpha = 0.677$)				
I feel confident finding health resources on the Web by myself.	4.15	0.730	0.356	0.546
I feel confident finding health resources on the Web as long as I have plenty of time to search.	3.72	0.885	0.365	0.538
I feel confident that I could find health resources on the Web using a general search engine (ex.: Google, AOL, Yahoo).	4.10	0.846	0.277	0.575
<i>Personal Health Information Outcomes Expectancy ($\alpha = 0.919$) $n=119$</i>				
Find current information like health news, new drug discoveries, clinical trials, and epidemic outbreaks.	3.53	1.206	0.788	0.902
Get information about medications, devices and health services.	3.69	1.110	0.726	0.909
Get immediate knowledge of big health news events.	3.35	1.190	0.721	0.910

Get health and drug information you can trust.	3.67	1.009	0.749	0.906
Find health information that is new to you.	3.75	1.035	0.846	0.897
Learn about controversial health information.	3.61	1.090	0.808	0.900
Learn about healthy lifestyles (including nutrition, exercise, prevention)	4.07	0.989	0.615	0.919
<i>Perceived Impact of Using Health Web^a (6-items α =0.624; 5-item α=0.651) (n=119)</i>				
...I feel I have more power to make decisions about my health.	4.01	0.719	0.531	0.522
...can help me talk with my doctor about my health	4.08	0.798	0.449	0.545
...I feel that getting the information is overwhelming ^b	2.33	0.922	0.236	0.630
...makes me confused as to the right course of treatment for my disease. ^b	2.27	0.918	0.298	0.605
...makes me aware of conflicting medical information about my disease and its treatment.[removed item]	3.55	0.880	0.172	0.651
...helps me take better care of my own health.	3.95	0.832	0.528	0.510

a: The indication mentioned a preceding item statement: "Using the Web to find health information..."

b: Negatively worded items (reverse scoring: 5 = strongly disagree to 1 = strongly agree)

c: Results are reported for each individual total scale.

Table 5.3 Factor Analysis of the eHealth Self-efficacy Scale

					Rotated Component Matrix ^a	
					1	2
Factor 1: External support						
I feel confident using a new health Web site I have never used before.					0.236	0.709
I feel confident finding health resources on the Web if the Web site had a Frequently Asked Questions (FAQ) section.					0.010	0.822
I feel confident that I could find health resources on the Web if I had someone to call or email if I got stuck.					-0.100	0.773
Factor 2: Self-control						
I feel confident finding health resources on the Web by myself.					0.886	-0.029
I feel confident finding health resources on the Web as long as I have plenty of time to search.					0.572	0.261
I feel confident that I could find health resources on the Web using a general search engine (ex.: Google, AOL, Yahoo).					0.857	-0.084
					Correlation Matrix	
	Mean	SD	Eigenvalue	% Variance explained	Factor 1	Factor 2
1. External support	10.07	2.013	2.035	33.915	1.0	
2. Self-control	11.97	1.910	1.728	28.798	0.110	1.0
Total SE scale	22.02	2.928	-	62.713	-	-

a: Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser

Normalization.

Table 5. 4 Mean scores, Reliability, Discriminant and Convergent Validity of the eHealth Self-efficacy Scale

Measure (α)	Mean	SD	Correlation Matrix								
			1.	2.	3.	4.	5.	6.	7.	8.	9.
1. eHealth Self-efficacy (0.597)	22.02	2.928	1.0								
2. General Self-efficacy	4.50	0.851	0.336**	1.0							
3. Computer Anxiety (0.939)	3.73	1.777	-0.238**	-0.470**	1.0						
4. PIO-Health ^a (0.919)	25.67	6.271	0.343**	0.219*	-0.124	1.0					
5. Perceived Impact (0.651)	23.00	2.997	0.323**	0.250**	-0.128	0.498**	1.0				
6. eHealth Use	3.07	1.118	0.210*	0.079	-0.145	0.484**	0.411**	1.0			
7. Total weekly Internet Use (hours)	17.76	18.473	0.080	0.136	-0.068	0.278**	0.106	0.232**	1.0		
8. Weekly emailing (hours)	7.80	10.214	0.040	0.044	-0.011	0.229*	0.073	0.192*	0.780**	1.0	
9. Weekly Internet not emailing (hours)	10.14	12.361	0.071	0.158	-0.116	0.150	0.090	0.223*	0.853**	0.338**	1.0

**Correlation is significant at the 0.01 level (2-tailed).

*Correlation is significant at the 0.05 level (2-tailed).

Off diagonal elements are correlations among constructs.

a: PIO-Health: Personal Health Information Outcomes Expectancy

CHAPTER 6

EFFECTS OF EHEALTH INFORMATION ON MEDICATION ADHERENCE, KNOWLEDGE, AND ATTITUDES IN ADULTS WITH CHRONIC DISEASES. A RANDOMIZED TRIAL ¹

¹ Provost M., Watson, R.T., Galen, R., DiPiro, J.T., Martin, B.C., Zinkhan, G. and Perri III, M. To be submitted to *Journal of Medical Internet Research*.

Abstract

Background: Despite the large proportion of Internet users seeking health information on the Internet, little is known about the impact of this eHealth behavior on patients' attitudes, knowledge and health behavior. While non-adherence with prescribed treatment is a public health concern, knowledge influences patient's adherence to medications. Integrating Web health information in patient care may be one of the solutions to encourage better self-care.

Objective: To evaluate the impact of eHealth information on medication adherence, disease knowledge and the patient-pharmacist relationship. **Methods:** A randomized controlled trial was

conducted with patients recruited from pharmacies, a cardiac rehabilitation and adult Fitness Center, a senior group and a large multinational corporate headquarters. Eligible participants had Internet access and were taking prescribed medications for the treatment of high cholesterol, hypertension and/or diabetes. The intervention group was encouraged to visit the study Web portal 4 times. The portal provided links to eHealth information sources and tracked usage by participants over 2-month period. Internet-based surveys assessed medication adherence, disease knowledge, eHealth and adherence self-efficacy, and eHealth use.

Results: Eighty-one patients (38 Intervention; 43 Control) aged 32-87 years (Mean 56 yrs, SD 14.1) consented and returned the baseline questionnaire. Participants in the intervention group made a total of 184 Web visits including accesses to 353 linked pages. Each participant spent on average 3.0 min (SD 5.0) per page. There was no statistical difference in medication adherence, knowledge, or patient-pharmacist relationships detected in this study. Case-reports of clinically significant results were observed prospectively, showing an increased awareness about medication side effects, contacts with physicians, including the request of change in dosage of medication by a patient. **Conclusion:** Results indicate that Web-based information may serve as an additional pathway for patients to get useful health information. Integrating the use of eHealth in clinical practice may benefit patients taking chronic prescribed medications.

Nonetheless, there exist great challenges as to convince patients to self-educate using reliable eHealth information. Recommendation for future research are provided.

Keywords: eHealth, medication adherence, self-efficacy, health information, Internet, pharmacy, prescription drugs.

Introduction

Although millions of Internet users worldwide seek health information each day, little is known about the impact and usefulness of eHealth information seeking behavior on patients' behaviors and outcomes [1]. A gap in knowledge exists and more research is needed to further understand eHealth behaviors and the impact of these behaviors on patient health.

EHealth includes use of the Internet or other electronic media by the public, health workers, others to access health related information, services, and support [2-4]. EHealth seekers consistently report in polls and studies, receiving benefits from using eHealth information, as well as changing their health behavior as a result of their Internet findings [5-14]. Although there is no good evidence of any harm caused by using eHealth information, there are also few rigorous studies showing benefits from eHealth information [15-16]. Evaluations of EHealth systems and services must move beyond testimonials and web site hits [4]. As randomized controlled trial remains the gold standard, this strategy may be applied for evaluating the effectiveness of web-based intervention or Web site [17]. There is, to our knowledge, no evaluation to date that looks at the impact of the use of eHealth information from several Web sites in an experimental design.

Benefits and Risks of eHealth Information Use

The recent expansion of Internet technologies embraced by the general public has opened up access to an extensive, almost unlimited, amount and variety of health information

that was previously restricted to health professionals. The Internet can be seen as a solution to resolve the information gap but as a potential risk due to misinformation related to unreliable sources [18-23]. Lack of information or misleading information can lead to bad outcomes. For example, consumers can be misled by Web site's or vendor's claims that herbal products can treat, prevent, diagnose, or cure, despite regulatory prohibition of this kind of statement [24]. In fact, 39% of a sample of kava kava retail sites (24 out of 64 sites) failed to address statement linking the supplement to fulminant hepatic failure as warned by a Food and Drug Administration's advisory [24].

Empowered with more information, patients can take part in the decision-making process with their health care providers [25-30]. Patients with diverse illnesses (cancer, diabetes, HIV/AIDS, cardiovascular disease, rheumatoid arthritis) and those who required invasive medical procedures gained health benefits from having increased access to health information about their conditions [31-37].

Information and Medication Adherence

Patients' lack of belief in medication benefits and lack of information about a drug are two of the most important determinants of medication adherence [38-42]. Medication non-adherence, possibly as a result of patients' low information levels, is considered a major public health problem in addition to the financial burden estimated to be about \$100 billion per year in health care and productivity costs [41, 43]. For the individual, being non-adherent may lead to reduced health benefits from medications that are effective in fighting morbidity and mortality.

Several factors are reported to increase non-adherence: patients may misunderstand the condition or treatment, deny the illness due to a lack of symptoms or perception of drugs as symbols of illness, lack of involvement in care plan, or face unexpected adverse drug reactions [44]. In familial hypercholesterolemia, Rand observed that patients needed to be convinced that their lipid-lowering treatment is necessary in order to ensure good adherence [45].

Although the problem of non-adherence is complex, the solution must provide simplicity for the patients. Proposed solutions include short-term regimens, fewer doses per day, lower medication costs, easy-to-use packaging, reminders, tailored interventions, patient education, and patient satisfaction measurement [46]. Clinical pharmacy services (medication histories and review, optimization of therapy to achieve desired outcomes, and reduction in adverse medication events) are beneficial to enhance medication adherence [47]. Interventions with written educational material, telephone reminders, group education, and one-to-one sessions have an effect on medication adherence [48-50].

The Internet, with its extensive visually appealing, interactive and written eHealth material, may be an additional pathway improving patient knowledge [51], which influences patients' attitudes toward prescription medication and medication adherence.

Objective

This study is a randomized controlled trial to evaluate the impact of eHealth information available on Web sites. The aim of this project is to determine the impact of 'eHealth Information Seeking Behavior' on medication adherence, disease knowledge and patient-practitioner interactions. This aim will be investigated by examining the outcomes of an experimental manipulation of eHealth information on a patient population.

Materials and Methods

Participants

Eighty one patients with Internet access taking prescribed medication for hypertension, diabetes and/or dyslipidemia, were recruited at four types of sites. Subject recruitment took place in 8 community pharmacies (3 chain stores, 5 independents), a senior community group, a Cardiac Rehabilitation and Adult Fitness Center located in Northeast Georgia, and a large multinational corporate headquarters in Atlanta, Georgia.

Eligibility criteria included patients over the age of 18 who were taking prescribed medications in one or more of selected chronic conditions (hypertention, diabetes and/or dyslipidemia) with Internet access. Participants signed consent forms for participation and authorization to release medical information to the researchers. The study was compliant with HIPAA (Health Insurance Portability and Accountability Act) and was approved by the University of Georgia IRB (Institutional Review Board), participating pharmacy managers or district managers, and legal departments of the pharmacy chain and the workplace in Atlanta.

Design

Following the initial eligibility screening by the principal investigator or pharmacists, participants were randomized to one of two treatment groups: eHealth information (intervention) or routine information and care (control). All participants had Internet access at home. The intervention group accessed the study Web portal, while the control group was not directed to access eHealth information.

Recruiters gave to eligible volunteers a pre-randomized, numbered, sealed envelope containing the research material. Randomization followed a random permuted blocks method. This method allows to allocate an equal number of patients to each of the two treatment groups (eHealth intervention or control) every time there are four envelopes distributed at a recruitment site. This method was chosen to reduce guessing of the next assignment group by the recruiter, which can introduce selection bias [52-55].

Participants were provided with the consent forms, a first paper-based survey marked with business reply mail, and instructions for the project. A \$10 gift-card was given to each participant recruited at the headquarters. The second and final survey was sent to the participants after 10 weeks, so that two prescription refills could be obtained during the course of the study. The link to the survey was first sent by email (online version developed using PhpSurvey 2.0, [56]) with a follow up reminder sent 3 days later. Participants were contacted by

telephone to increase awareness of the email sent. The email mentioned the alternate option of receiving the paper format of the questionnaire. This was required by the Institutional Review Board to offer various levels of security of data transmission. Therefore, some participants received the paper-based format for example if they have concerns or technical difficulties with the online questionnaire.

Intervention

Patients randomized in the eHealth intervention group were asked to visit the study Web portal, available at www.RxLinx.org, at least 4 times in the 2-month period. Participants received login procedures in the research material and via email reminders when a participant did not login two weeks after recruitment. In case of difficulty accessing the site, a cellular phone help number and email contact were provided on the login page to reach.

Individual email reminders to visit the Web portal were sent to the study participants every 7 to 10 days to invite them to do their 4 visits or more if needed. Reminders were not sent anymore when a participant emailed us saying that he or she had already completed 4 visits. This was verified with the real time log of the Web portal. The control group received one email at the beginning to thank them for their participation and remind them to complete and return the first survey (as in the first email to the intervention group).

Study Web Portal

Development and Purpose

The study Web portal, named RxLinx.org¹, was created by the principal investigator to provide participants access to a representative sample of Web sites found online by Internet users seeking prescription drug or disease information. These Web sites, named “sources” in

¹ RxLinx.org is currently not publicly accessible. Login access can be requested by emailing the contact author.

this paper, were thought to be representative of what Internet users should retrieve when seeking prescription drug information Web sites using search engines. Retrieval and selection of the Web sources followed a structured method using different key words in searches in several search engines [57]. The keywords to retrieve the Web sites were selected as if users sought “medication information”, “prescription drug information” or “medicine information”. Web sites with a commercial objective of selling medication were excluded, and included only if a privacy policy was accessible from the homepage of the site.

Since the selection of Web sources aimed to mimic the findings of users seeking drug information online, Web sites provided by the pharmaceutical industry and official organizations (for example, the American Heart Association) were included. Examples of Web sources are presented in Table 6.1.

The purpose of the Web portal was to guide the participants to existing Web sources of information and observe eHealth information seeking behaviors. To attain the latter objective, an essential feature of the Web portal was the data tracking of usage by each participant of the intervention group. Web log were organized in a table to extract data in a format compatible for Excel spreadsheets. RxLinx.org followed the Health On the Net Foundation’s (HON) HONcode Principles, and was reviewed by HON and accredited with the HONcode.[58] The active seal of accreditation was visible on the login page and all internal pages. The URL (Uniform Resource Locator) www.RxLinx.org was redirected to www.RxLinx.uga.edu, hosted by the University of Georgia’s servers. This approach was chosen to increase name recall of a shorter name for the participants.

Content

For the purpose of this project, dyslipidemia, hypertension, diabetes and arthritis rheumatoid and their prescribed drug treatments were covered on the Web portal. This portal provided links to web content by links to external Web sites. No health content was provided on

the Web portal. The Web portal consisted of medication specific pages presenting a list of 9 links to Web pages from generic sources of drug information (Fig. 6.2). Examples of Web pages are also presented in the Multimedia Supplement.

A medication specific source of information was considered “general” if it was not provided by the manufacturer of the drug. “Brand” sources were also suggested to guide users to direct-to-consumer Internet information (DTCII) provided by pharmaceutical companies. The links to the brand sources were listed in a separate box after the list of general sources.

There were also disease-specific Web pages (high cholesterol, hypertension, diabetes and rheumatoid arthritis) on the study Web site offering links to condition-specific Web pages of the same general sources as the medication-specific pages. In addition to the general sources, the lower box presented links to national organizations for the conditions (Table 6.1).

Web Design and Login Access

To avoid preferential treatment of one information provider based on list order, all links to general sources were randomly reordered each time users refreshed a page. In all cases, the sources and URL’s of the linked pages were shown to the users. No content was created or provided on the study Web site due to the objective of collecting usage measures of a sample of health information available on the Internet.

Login was simple and intended to identify respondents for tracking purpose. Passwords were provided to the participants in their individual research package and they picked their username following certain rules (LASTNAME##, where ## was replaced by the last two digits of their birth year). Passwords were the same, but this was not known to respondents.

Web Portal’s Link and Privacy Policies

No individual information was asked on the study Web site since data collected could not be encrypted or stored on a secured server. Participants were advised in the consent form

about confidentiality limitations due to the Internet technology. A brief privacy policy was also mentioned on one of the internal pages of the portal.

In order to respect copyrights the Web sites used as a source of information, no content was copied, downloaded, saved or cached on the study servers. The study portal suggested links to the external Web sites. Sources and URL's of the linked pages were shown to the users. Therefore, tracking of usage was limited to the use of the study Web portal. Users could not be observed while using external sources. However, the external sources opened in a new browser window that allowed measurement of the duration of use until the next action on the study Web site. An assumption was made that users were active until they click the logoff button at the end of their visit.

Dependent measures

Medication adherence, disease knowledge and patient-pharmacist communication were the three main dependent measures. Knowledge and patient-pharmacist communication were assessed by self-reported post-test only questionnaire. Adherence with prescribed regimen was measured using a self-reported scale that had support for validity and reliability ($\alpha = 0.82$) and pharmacy refill records when available [59].

Three parallel questionnaires were created to assess disease specific (diabetes, high cholesterol and hypertension) and general cardiovascular knowledge. The questionnaires were pre-tested with students in pharmacy or other departments. Each questionnaire had 10 items: 3 identical items about side effects of medication, myocardial infarction and stroke; 6 similar items but individualized for the disease, and 1 item that was similar in hypertension and diabetes (about biometrics) but different in dyslipidemia where an item about the "good and bad" type of cholesterol was asked. The domains covered in each questionnaire related to cardiovascular risks, duration of drug treatment including the occurrence of side effects, physiology, biometrics, lifestyles (diet and exercise), and disease morbidity.

A measure of eHealth information seeking self-efficacy was previously developed and shows evidences of construct, discriminant and convergent validity and reliability ($\alpha = 0.62$) [57]. The eHealth self-efficacy scale was originally developed based on Internet and Computer Self-efficacy instruments [60-61]. A summated score was computed (maximum score of 30) at baseline.

Sample Size Estimates

The intervention in the current study may be classified as educational in nature (not behavioral or affective). The expected effect size of this type of intervention was reported to be 0.28-0.35 for indirect adherence measure studies (prescription refills) and 0.14-0.20 for subjective measures (self-report) [48]. The effect size rises above 0.40 when the intervention involved the provider (indirect measure of adherence).

Providing a power of 70% ($\beta-1=0.70$) for 95% confidence ($\alpha_2=0.05$) and a medium expected effect size ($d=0.30$), a sample of size 140 participants in each group would be required [62]. In these same conditions, if the effect size is larger at 0.40, a sample size of 80 participants in each group would be needed.

Data Analyses

Data analyses included descriptive statistics of the sample characteristics, statistical testing using one-way ANOVA when the assumptions were met, t-tests, and non-parametric analyses for categorical variables. The reliability of scales was evaluated with Chronbach's alpha. Pearson's correlations were used to assess validity of some self-reported measures. Analyses were performed using Statistical Package for the Social Sciences (SPSS 12.0, Chicago, Ill.), and followed an intent-to-treat (intent-to-inform) principle using also non-users of the Web portal as part of the intervention group.

Results

Overall, 189 eligible participants with an interest to participate received the consent forms and research material after initial screening for eligibility. Although there were 7 pharmacies collaborating for the recruitment of participants, the numbers of eligible participants who showed interest in participating were disappointing ($n=35$). Three of the pharmacies did not find any eligible participant to give the consent forms and research material. One other pharmacy in a rural area only succeeded with one participant recruited. The pharmacists explained it by a lack of time to discuss the project in addition to their pharmacy duties, or a lack of access to the Internet by their elderly or lower income clientele. Another pharmacy was successful in recruiting participants but stopped recruitment rapidly due to a change in the pharmacy's computer system that caused an increase in the workload. One single pharmacy distributed the largest number of research packages due to their high volume of distribution in a day reaching up to 400 prescriptions refilled. Although they gave an announcement cards about the study to several patients who refilled a medication in one of the selected diseases, customers did not volunteer to participate. A larger proportion of people were eligible and willing to participate at the other recruitment site with the presence of the principal investigator.

Even with a smaller sample than first planned, it was decided that this work had valuable meaning for several reasons. To the best of our knowledge, there is no study reported tracking patients' eHealth seeking behavior in a prospective manner with the intention to evaluate the impact on medication adherence, knowledge and other aspects. Also, there is a lack of information on the potential effect size of an eHealth information intervention. The process and methodology can benefit other researchers in the field of eHealth to generate future studies to address the gap in evidence to know if the use of the Internet for seeking health information has any benefits, or cause any harm, to the daily millions of users.

A total of 81 participants responded to the baseline survey (51 men (63.0%) and 30 women). This showed 50% declining rates in both treatment groups. Figure 6.1 presents the

flow of participants during the study. The age of the participants ranged from 32 to 87 year old (Median = 54.0, Mean = 56.1, S.D.=14.1). The respondents were well educated: 71.6% were college graduates or post-graduates and an additional 21.3% had some college education. They were experienced with the Internet in general. About half of the participants had high-speed Internet connections, and two thirds accessed the Internet from home for their personal searches. An additional 15% accessed it about equally from home and work. The two study groups did not differ on the key baseline measures (Table 6.2).

Seventy percent (70.4%) had looked up health information on the Internet before, while an additional 11.1% were indirect users because they received web information from a friend but didn't look up themselves. At baseline, of those who had looked for eHealth information before (n=58), more than half (53.4%) reported that getting health information on the Internet only improved a little, or not at all, the way they take care of their health.

Two-month follow up data were collected for 68% of the participants (n=55). Drop out rates were similar among the intervention group and the control. Some participants completed the paper-based survey due to technical difficulties when submitting their survey responses that failed to be transmitted in the database. Remaining analyses were done on participants who completed both questionnaires.

Each participant was classified into one of three disease-categories (diabetes, high cholesterol, or hypertension) in order to determine which knowledge questionnaire they would receive at follow up. (Table 6. 3)

eHealth Use

Among the 38 participants randomized to the eHealth information group who completed the baseline questionnaire, 31 (81.6%) visited the study Web site at least once during the study period. An additional 5 participants used the Web site although they did not complete the baseline survey and were therefore not considered in the final sample for analyses.

Nineteen participants (61%) visited the study Web portal four times or more. From the Web portal, they used a total of 376 linked pages. Each participant accessed the portal on average 5 times (SD=2.8) where they accessed an average total of 12 Web pages (SD=10.6).

To assess if there was any contamination of the control group by using the Internet to access eHealth resource, self-report levels of usage was evaluated. A majority of respondent (69%) in the control group reported to have rarely or never sought eHealth since the beginning of the study. One person (3.4%) reported having sought eHealth often or occasionally in the control group while 17 persons in the intervention group did so (65.4%). Categories of responses were grouped (often-occasionally and rarely-never). The proportion of people per level of use among the groups varied significantly ($n=54$, $\chi^2=7.348$, $p=0.007$). Simply by taking part in the project, the control subjects were not influenced to seek eHealth on their own.

The self-reported measure of eHealth use was validated with the direct measure of Health use (Web log) among the intervention group ($n=26$). The number of external pages visited on the portal was strongly and significantly correlated with the self-reported measure of frequency of use of health ($r=0.76$, $p<0.0001$). A moderate correlation was also detected between the number of external pages visited on the portal and the self-reported measure of eHealth use ($r=0.66$, $p<0.0001$).

Evaluation of eHealth Use across Web Resources

This is the first longitudinal study observing ePatients seeking health information on the Internet. Therefore, some descriptive statistics of the eHealth seeking behavior are of interest to understand the nature of the exposure to eHealth in this natural experimental setting. The summary of eHealth use across sources is presented in Table 6.5.

Across the 9 sources suggested within a medication specific or disease specific Web page of the portal, 38.7 to 74.2% of individuals visited each source ($n=31$). MayoClinic.com, WebMD, and RxList.com were selected by the largest proportion of participants (74.2%, 64.5%,

and 61.3%, respectively). People accessed the largest number of pages from these same three Web sources (Table 6.5, Fig. 6.3). There is an apparent trend in the selection of sources according to the order of presentation in the list of suggested links (Fig. 6.4). Most selections were listed first when selected by users, and frequency of selection progressively decrease as the suggested source is lower in the list of suggested sources.

Only 5% of visits were to links provided by pharmaceutical companies (18 out of 375 links visited) by 12 participants (38.7%, n=31). However, several brand medications did not have direct-to-consumer eHealth information available online. This is the case for older medications now available as a generic product (for example, Lasix®, furosemide). Only one person clicked to verify the active HONcode accreditation logo presents on every page of the study Web site.

Average time spent per page ranged from 1.44 minutes to 3.02 minutes across general sources. Figure 6.5 presents the average time spent per source-page, the range and outlier participants who looked for longer periods of time.

Due to the study Web site design, medication lists were more prominent to the users than disease specific Web pages. Therefore, this may explain in part why people mostly accessed medication pages rather than disease pages.

Outcome Evaluation of eHealth Use

Tests were conducted on the two main outcomes of interest: medication adherence and knowledge. A summary of results is presented in Table 6.4.

Medication Adherence

There was no statistical difference between the control and experimental conditions on self-reported measures of medication adherence and medication adherence self-efficacy. There is not enough evidence to conclude that the eHealth exposure had an effect on

medication adherence and adherence self-efficacy. This indicates a lack of treatment effect from eHealth use. (Table 6. 4)

The reliability was tested for both scales. The Hill-Bone Adherence and the Cook Adherence Self-efficacy scales presented good support for internal reliability ($\alpha=0.743$ and 0.814 , respectively). The scales were tested for their concurrent validity. The adherence scale and the adherence self-efficacy were significantly correlated (Pearson corr. = 0.64 , $p<0.0001$)

Knowledge

The 6-item measure of self-reported learning was evaluated for its internal reliability. One item was removed based on its negative influence on internal reliability when removed from the scale. The final scale had a Chronbach's alpha of 0.78 . A summated score could range from $5-25$ (observed range $9-22$), where a higher score indicated higher Perceived Learning. There was no significant difference between the Perceived Learning in patients of the intervention group and the control group ($p>0.05$).

Knowledge means during pre-test were significantly different between the groups of students ($p<0.001$). Items with higher item difficulty score (~ 1.0) were removed, as they would not help differentiating respondents. The final instruments had 10 items each and were used in the study.

The mean scores on the knowledge measure were 16.31 (3.18) and 15.86 (4.00), for the eHealth and control group, respectively (Maximum score of 20). There was no significant difference between the means ($p<0.05$). In both group, 69% respondents were above the average knowledge score. There was no statistical difference in the proportion of people below and above average among the between the groups ($p>0.05$).

Concurrent validity was tested between the knowledge measure and the self-reported perceived learning. Both instrument significantly correlated (Spearman corr. = 0.40 , $p=0.003$).

One open-ended item asked participants to describe if there was anything that stands out in their mind that they found on the Internet since the time when they were recruited in the study (Table 6.6). Based on a brief qualitative evaluation, comments among the intervention group appear stronger than people from the control group reported. One of the comments from a participant exposed to eHealth information reflect a direct impact of eHealth information on a potential error of dosing of a newly marketed lipid lowering agent. The participant acted following reading eHealth information and contacted the physician. This is a case-report of an impact of eHealth on the patient-physician relationship. In this prospective study, some patients exposed to eHealth information in the intervention group reported having an increased awareness of medication side effects, variety of treatment for their disease, and heart disease. However, participants also reported some relatively negative comments related to the difficulty of finding eHealth information.

Attitude towards eHealth information

Among respondents who sought eHealth information (intervention, n= 21, control, n=15), 19.2% participants in the intervention group were very satisfied compared to only 3.4% in the control group. However, 24.1% participants in the control group, and 26.9% in the intervention group were somewhat satisfied with the information found about the treatment of their chronic conditions. The level of satisfaction did not differ between the control and the eHealth group ($F_{35, 0.05}=0.084$, $p=0.774$).

Perceived Benefits ($\alpha=0.75$) from the use of eHealth did not differ between the groups ($t_{52, 0.05}=0.415$, $p=0.680$, $n=53$). People who were exposed to eHealth information during the study did not have a different perceived benefit of using eHealth information (Table 6.4).

There was no indication of harmful effects observed based on self-report measure of being worried following reading information about their medication online. In the intervention group, 61.9% of people in the reported that the information found did not at all cause worries

(n=36), while among those who sought eHealth information, 60% of people in the control group reported the same level (n=15). The rest of respondents answered “a little worried”, and no one respondent reported that the information they found online about their medication caused them to be “worried” or “a lot worried”. There was no statistical difference across the categories and groups ($\chi^2_{1, 0.05}=0.013$, $p=0.908$).

Patient-Pharmacist Relationship

The number of questions asked to the pharmacist (categorical variable), as an assessment of the patient-professional relationships, was not found to be statistically different between the groups. Most people (89%) in each group reported either having not ask questions at all, or not having talked to the pharmacist the last time they went to refill their prescribed medications. Three respondents in each group (11.5% Intervention and 10.3% control) reported having printed pages of information found online to show their doctor or pharmacist.

Discussion

Challenges and Innovation in eHealth Research

This study is one of the first to evaluate a multitude of health Web sites with an innovative strategy to investigate the impact of eHealth information use on patients' outcomes and attitudes [17]. Although not statistically significant, findings are relevant to the field of eHealth research due to the method, measurement, and results helpful.

The target population of this study was patients taking prescribed medications, and having Internet access, but who were not necessarily seeking eHealth at baseline. The recruitment strategy increased the external validity of the results by its generalizability to Internet users who may not turn to the Web for eHealth. The approach allowed recruitment of elderly Internet users who may be unlikely volunteering to online health research. Although Internet studies have an appealing factor of recruiting large online sample [17], there are

challenges to manage the risk of selection biases towards younger, experienced user or eHealth seekers.

One of the key strength of this study is the innovative use of a Web portal to permit the monitoring of eHealth use across various Web sites. The Web portal was designed to guide participants to a sample of links to eHealth content and to provide Web log for analyses. Further studies could use this approach to gain understanding of the use of current eHealth content by patients.

Since little is known about the effect of eHealth use, it was challenging, in the context of this randomized controlled design, to set a “dosage” – level of information exposure – for the intervention. Dose-response was not evaluated with the use of different levels of exposures due to the gap in knowledge about eHealth behaviors. Before this study, it was unknown as how participants would accept any Web usage requirements of a research study protocol. Some previous intervention studies reported a lack of usage by the study participants and decrease usage overtime [63-65]. The fact that most participants used the study Web portal more often than requested indicates that a more demanding task could have been imposed. This level of usage indicated that eHealth use responded an information need among patients taking prescription medications for chronic diseases.

The level of exposure to eHealth information, as an experimental intervention, can also be quantified with respect to the duration of a longitudinal study. A longer study would increase the number of times the participants would use eHealth information. This could improve the recall of the information related to learning by repetition. Although a longer study would have been logical for evaluating knowledge and medication adherence, it would be challenging to impose the eHealth information seeking task for a longer period. There would be a threat to the internal validity in a longer study, incorporating maturation biases [66-68].

eHealth Information Seeking Behaviors

People used several sources of eHealth information for a short period of time rather than navigating one source for a longer period. Results of this study indicate that ePatients selected eHealth sources of information based on the upper ranking position in the list of suggested links. However, brand recognition seems to play a role in their selection as WebMD, MayoClinic.com and RxList.com were most popular by attracting greater number of participants, and greater time spent. RxList.com popularity as a source of information may be the result of an instrumentation bias caused by the influence of the name of the study web site, RxLinx.org. These findings support that when having the choice, ePatients most likely select the source based on their pre-existing awareness of the information provider. Further research is needed to evaluate if this eHealth seeking behavior stands when people select from lists generated as a result of their searches using search engines. These results were observed in the context that 9 general sources and pharmaceutical companies' Web sources for each prescribed drug or illness were suggested to the users.

The fact that only one person in this sample (n=31) verified the HONcode logo during the study may be due to the high credibility inspired by the study Web site as part of a research project with the University of Georgia. People may have been confident in the validity of the logo and not expressing the need to verify it. Or, it may also be explained by a lack of awareness of the HONcode by participants in this sample.

The use of brand-specific Web sources by pharmaceutical companies was low in this study. As other results showed, the position may have influenced the selection by participants since brand-sources were fixed (not randomly reordered) at the bottom end of the page following the list of the 9 general sources of information. Also, further evaluations of the data are needed to deeply investigate if brand-information was available for the medications participants were taking.

Results of time spent using a Web source should be viewed with caution. In fact, there was no adjustment for people having high speed or modem connection as this may influence the time spent, but not necessarily the “active” time navigating or reading the content. Also, use may be prolonged by people printing information to read at a later point when offline.

Although anecdotal, some participants reported not knowing what else to seek other than information about their medications on the suggested Web sites. This unawareness of the availability of content, or simply no need of information, may partially explain the short time spend doing eHealth seeking. A more structured and tailored intervention by means of topics suggested to participants to guide them in their learning syllabus could potentially increased content exposure and likelihood of detecting an effect. However, the results may indicate that Internet users may not know what to learn about their health online, and may not be aware of the variety of information available to them on Web sites. Health professionals, Web providers, or improved information system tools may be helpful to guide patients in their eHealth information seeking.

Lack of Treatment Effect

Part of the reason for the failure to detect a treatment effect of eHealth information use in this study relates to sample size, and high attrition rate. However, exploratory analyses of eHealth seeking behaviors among people in the eHealth exposure group bring useful implication to researchers, health care professionals, and Web information providers, as how people use the Web to get medication and disease information.

At baseline, participants had been taking their medication for a relatively long period (average 48 months). Therefore, it is likely that this sample was already convinced to take their medication as recommended. The study would gain in targeting patients with newly prescribed medications who are more likely to stop taking their medications over the first few months.

The failure to detect a difference in knowledge between the groups is in part due to the pre-existing knowledge of the participants who have a high level of education. Also, the volunteers were recruited in environments where health promotion programs were in place, and education had been stimulated. These factors may have increased their learning about their disease and lifestyle even before the study. This reduced the chance of detecting a small effect related to the use of eHealth on knowledge. Also, the instruments assessing knowledge could have included more difficult items to increase variability in responses among participants.

The control group was assumed to receive normal care and information related to their prescription medications and conditions. Alternative forms of exposure to health information – broadcasted (eg. Radio or television programs, advertising, or news), printed (magazine, newspapers, medication leaflet), or other people (friends, relative, health providers) – may confound the exposure to eHealth information and reduce the likelihood of detecting an effect.

Access to eHealth in Clinical Care

Several barriers exist for accessing relevant health information and access to the Internet itself remains a barrier for most people since users have been characterized as more educated and with higher incomes than non-users [69]. As seen in the sample taking part in this research, Internet users do not necessarily seek eHealth information at its full potential. Existing eHealth information may have benefits for patients who can find and read reliable Web resources. Health providers may increase the satisfaction of their patients by suggesting them where to go to seek further information about the disease. In fact, 29.1% of participants (n=55) reported being very dissatisfied or dissatisfied with the level of information provided at their pharmacy about their medication. Pharmacists would enrich their provision of care by guiding people to use eHealth information.

Evaluating and integrating eHealth information into patient care is not as straightforward as it may seem. One of the strengths in this study relates to the recruitment in various sites like

in the workplace, pharmacies, senior community groups, and fitness center, to access a broad range of people. However, the study sample size also demonstrates the difficulties in reaching patients outside of the scope of a health care provider in order to do research. This is an obstacle to perform research as the impact of eHealth use should be evaluated not only with Internet users, but in all patients that could eventually benefit from eHealth information seeking. However, the complexity still remains for reaching population in greater need of health information who may benefit the most from it, but may not have access to the Internet, not know how to use it to seek eHealth information in their own language, or may be illiterate.

Limitations

This study would have been improved with larger sample size. Persistence with taking medications as prescribed in a continuous manner could not be assessed during this short-term study. Initial adherence to prescribed regimen, referring to the early adoption of a new prescription, may have greater chance of being influenced by information about the medication, but bring challenges in the recruitment of such population. Careful attention should be taken in future study as for defining the eHealth intervention. For example in the current study, intervention participants received more reminder emails intended to remind login to the study Web site. This reminder can be considered as part of the intervention as it could have influenced one of the outcomes of interest, medication adherence, by reminding participants to take their medication that day.

Generalizability of the results is limited due to the sample characteristics (high income, highly educated, males). Sample bias exists as people were recruited on a voluntary basis. Although this does not affect the internal validity, there is a possibility that highly motivated participants are intrinsically more likely to take their medications as prescribed, or to learn about their diseases since they were diagnosed.

Contamination of the control group by exposure to eHealth content can reduce the chance of detecting differences between the groups [17]. One of the open-ended comments of an individual in the control group confirmed it, as well as self-report measures of using occasionally Web sources of health information by 31% of the control group. However, by using 2 separate consent forms, there was less emphasis about the intervention (eHealth use in the study Web site) known by the control group. This reduced the risk to motivate control subjects to seek eHealth resources elsewhere during the study.

Future Research

As presented in the discussion, several aspects were learned from the processes and results of this study on eHealth information seeking behaviors to build on knowledge about eHealth and eHealth information seeking. The study could be reproduced with an online only sample to reach larger sample size but this may bring other limitations or threats to the generalizability of the results to the adult population.

Further, a similar study would benefit from greater experimental control of the exposure by requesting different levels of usage in multiple treatment groups. Structured and tailored eHealth information interventions may increase content exposure and likelihood of detecting an effect. More studies are needed to evaluate attitudes towards seals of accreditation and its verification during eHealth information seeking.

Conclusions

Exploratory results indicate that people used several sources of eHealth information for a short period of time rather than navigating one source for a longer period. In this study, ePatients selected eHealth sources of information based on the upper ranking position of the suggested links, as reported in the literature on Internet use in general.

There was no more evidence that eHealth information about medication would cause people to worry about taking their medications. After being exposed to eHealth, people perceived eHealth as useful and were satisfied with the information they found online. These findings imply that ePatients may need greater guidance and encouragement from health professionals to use eHealth sources of information as part of their self-care and health education. Many clinicians have underestimated the benefits and overestimated the risk of eHealth resources for patients [16, 70]. Based on the comments received from participants exposed to eHealth information, and the level of usage of eHealth resources in this study, there is indication that clinicians could play a role in guiding patients towards eHealth information.

The process and results of this study support the idea that eHealth behavior research presents methodological challenges and benefit from applying rigor of evaluations, such as a randomized controlled design and using models from social science, behavioral psychology, and information systems [71].

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Conflicts of Interest

The authors are not involved in any manner with the Web sources of information selected, the pharmaceutical companies, or do not support any mentioned brands. Brand names mentioned are the properties of the respective companies. M Provost is professionally involved with the Health On the Net Foundation, Geneva. An independent HONcode reviewer evaluated the study Web portal.

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Abbreviations

DTC: Direct-to-Consumer; also seen as DTCA, DTC advertising of prescription medication.

DTCII: Direct-to-Consumer Internet Information provided by the pharmaceutical industry.

FDA: U.S. Food and Drug Administration, Department of Health and Human Services.

HIPAA: Health Insurance Portability and Accountability Act of 1996.

HON: Health On the Net Foundation.

SD: standard deviation.

URL: Uniform Resource Locator.

Table 6.1 Web Sites Sources* in the Study Web Portal RxLinux.org

Sources	URL's
<i>General:</i>	
Drugs.com	http://www.drugs.com
DrugDigest (by ExpressScript)	http://www.drugdigest.com
HealthAtoZ	http://www.HealthAtoZ.com
HealthSquare	http://www.HealthSquare.com
MayoClinic.com	http://www.mayoclinic.com
MedicineNet	http://www.MedicineNet.com
MedlinePlus (US Government)	http://www.medlineplus.gov
RxList.com	http://www.rxlist.com
WebMD	http://my.webmd.com/
<i>National Organizations:</i>	
American Heart Association	http://www.americanheart.org/
American Diabetes Association	http://www.diabetes.org
Medem (A physician-patient communications network by leading medical societies)	http://www.medem.com
<i>Brand:</i>	
Brands Web sites	For example: http://www.altace.com by Monarch Pharmaceuticals® and Wyeth® (ramipril), http://www.lipitor.com by Pfizer® (atorvastatin) http://www.glucophagexr.com by Bristol-Myers Squibb Company (metformin)
Additional DTCII**	For example: http://www.diabeteswatch.com/ by Aventis, http://www.mercksource.com by Merck & Co. Inc.

*All names and trademarks (site names, brands) are the property of the respective corporations or groups.**DTCII: direct-to-consumer Internet information by the pharmaceutical industry.

Table 6.2 Baseline demographics

Variables	Respondents survey 1 (n= 81)						Intervention vs. Control p-value
	Total		Intervention (n=38)		Control (n=43)		
	n	%	n	% ^c	n	% ^c	
Age	Mean 56.12 yrs	SD 14.09	Mean 54.79	SD 13.31	Mean 57.27	SD 14.81	0.432 ^a
Gender							
Male	51	63.0	20	52.6	31	72.1	0.070
Female	30	37.0	18	47.4	12	27.9	
Race/Ethnicity							
White	64	79.0	31	81.6	33	76.7	0.594 ^c
African American	9	11.1	5	13.2	4	9.3	
Hispanic/Latino	6	7.4	1	2.6	5	11.6	
Asian	2	2.5	1	1.2	1	2.3	
Education							
High school	5	6.2	3	8.1	2	4.7	0.123 ^d
Some college	17	21.0	7	18.9	10	23.3	
College graduate	20	24.7	13	35.1	7	16.3	
Post-graduate	38	46.9	14	37.8	24	55.8	
Missing	1	1.3					
Household income							
\$15,000-24,999	1	1.2	1	3.0	0	0	0.421 ^e
\$25,000-34,999	8	9.9	6	18.2	2	5.3	
\$35,000-49,999	13	16.0	6	18.2	7	18.4	
\$50,000-74,999	12	14.8	5	15.2	7	18.4	
\$75,000-99,999	13	16.0	4	12.1	9	23.7	
\$100,000 or more	24	29.6	11	33.3	13	34.2	
Missing/Refuse	10	12.3					
Health status							
Poor	2	2.5	1	2.6	1	2.3	0.693 ^f
Only fair	10	12.3	4	10.5	6	14.0	
Good	55	67.9	29	76.3	26	60.5	
Excellent	14	17.3	4	10.5	10	23.3	
Diabetes	20	25.0	11	28.9	9	21.4	0.438
High cholesterol	45	56.3	22	57.9	23	54.8	0.778
Hypertension	54	67.5	28	73.7	26	61.9	0.261
EHealth Self-efficacy score § α=0.72 (n=78)	Mean 23.38	SD 3.26	Mean 23.38	SD 3.19	Mean 23.39	SD 3.37	0.987 ^b
Internet experience							
<6mths	1	1.2	1	2.6	0	0	0.438 ^g
>6mths <2 yrs	6	7.4	3	7.9	3	7.1	
2-4 yrs	13	16.0	4	10.5	9	21.4	
>4yrs	60	74.1	30	78.9	30	71.4	
Missing	1	1.2					
Rx insurance							
all out-of-pocket	10	12.3	4	10.5	6	14.0	0.168 ^h
most out-of pocket	13	16.0	4	10.5	9	20.9	
insurance pays			30	78.9	28	65.1	
most	58	71.6					

§Total maximum summated score is 30. Groups were compared using F-test for continuous variable and chi-square for categorical variables. a: $F_{(0.05, 80)}$; b: $F_{(0.05, 77)}$; c: other races/ethnicity were grouped; d: high school and some college were grouped; e: income less than \$50,000 were grouped; f: Poor-only fair / Good-excellent were grouped; g: web experience less than 4 yrs were grouped.

Table 6. 3 Classification of Respondents in Disease Specific Groups

Groups	eHealth		Control	
	n	Responded n (%)	N	Responded n (%)
High cholesterol	18	15(83.3)	20	15 (75.0)
Hypertension	18	10 (55.6)	21	14 (66.7)
Diabetes	2	1 (50)	2	0
Total	38	26 (68.4)	43	29 (67.4)

Table 6.4 Outcome Results by Treatment Condition

	eHealth Intervention n=26		Control n=29		Test (p-value)
	Mean	SD	Mean	SD	
Medication Adherence ($\alpha=0.74$) (Possible range 6-16) ²	10.40	2.50	9.59	1.79	0.299 ¹
Medication Adherence Self- efficacy ($\alpha=0.81$) (Possible range 6-30)	11.15	4.86	9.90	4.13	0.460 ³
Knowledge	16.31	3.18	15.86	4.00	>0.05
Perceived learning ($\alpha=0.78$) (Possible range 5-25)	16.27	2.58	15.71	3.75	0.533
Satisfaction with eHealth information (Score range 1-5) ⁴	3.57 (n=21)	1.21	3.47 (n=15)	.834	$F_{35,0.05}=0.084$ (0.774)
Perceived Impac ($\alpha=0.75$) (Score range 5-25)	22.0	3.32	21.6	2.96	$F_{53,0.05}=0.172$ (0.680)

1: Mann-Whitney U, 2-tailed, $n_{\text{adherence}} = 54$, $n_{\text{adherence-self-eff.}} = 55$. 2: Lower score is more adherent.

3: Lower score is more adherence self-efficacy. 4: Higher score is more satisfied.

Table 6.5 Direct Measure of eHealth Use (Intervention group, n=31)

		Associations	Companies	DrugDigest	Drugs.com	HealthAtoZ	HealthSquare	Internal	MayoClinic.com	MedicineNet	MedlinePlus	RxList	WebMD	Total
Visitors	n		17	18	17	12	3	23	12	16	19	20	30	
	%		54.8	58.1	54.8	38.7	9.7	74.2	38.7	51.6	61.3	64.5	96.7	
Web link visited	n	7	18	40	26	26	21	3	54	24	31	42	56	348
Time spent (min.)														
	Total	48.7	56.3	64.5	31.7	50.1	65.8	2.6	183.6	87.8	78.25	128.4	142.2	940.0
Time spent per page (min.)														
	Mean	8.11	3.75	1.74	1.44	2.00	3.29	1.30	3.91	3.82	2.90	3.38	3.03	
95% CI, Lower bound		3.44	0.23	1.04	0.75	0.71	1.21	-7.38	2.72	1.44	0.66	0.51	1.73	
Upper bound		12.78	7.27	2.45	2.13	3.29	5.38	9.98	5.09	6.20	5.14	6.25	4.32	
SD		4.45	5.83	2.12	1.55	3.13	4.45	0.97	4.04	5.50	5.66	8.73	5.50	
N*	6	15	37	22	25	20	2	47	23	27	38	47		

SD: standard deviation; CI: confidence interval. Percentages do not sum to 100% because each individual could visit more than one source.*n represents the number of hits with a valid measure of duration, and were smaller samples due to participants not logging off but closing the browser window to exit.

Table 6.6 Participants' Comments* on eHealth Use per Group

EHealth Intervention group	Evaluation
<ul style="list-style-type: none"> ● During the term of this study, my doctor switched me from Lescol to Crestor. I learned from the web site that the dosage prescribed for Crestor was higher than the recommended starting dose. After informing the doctor, he lowered the dose for me. 	*****
<ul style="list-style-type: none"> ● One side effect of Actos is muscle tightness, which I do experience. Maybe it's just old age, but if it gets too painful I may stop the Actos and see what happens. 	****
<ul style="list-style-type: none"> ● That I should maintain a constant level of medication in my system for maximum benefit. 	****
<ul style="list-style-type: none"> ● All the answers I can find on the internet. 	***
<ul style="list-style-type: none"> ● The web is a great resource to find info about medications you are taking, and their side effects. 	***
<ul style="list-style-type: none"> ● there is a lot of good information out there 	***
<ul style="list-style-type: none"> ● Raised my awareness about the amount of information on medications, heart disease and care overall. 	***
<ul style="list-style-type: none"> ● I learned that with a bit of hassle, I can find out health information on the web but I found the medications sections confusing and cumbersome to maneuver. 	*
<ul style="list-style-type: none"> ● the different types of medicines for my disease 	**
<ul style="list-style-type: none"> ● always pay attention 	*
<ul style="list-style-type: none"> ● Information on the Web duplicates other sources of information about health issues, etc. Nothing new. 	*/_
<ul style="list-style-type: none"> ● I wish in the future when I get my new computer I could experience and have the chance to go into these Web sites <i>[paper-based]</i> 	*
<ul style="list-style-type: none"> ● The information is not in as user-friendly a model as it could be; either too simple or too complex. 	-
<ul style="list-style-type: none"> ● I was never able to find my particular drug on the website given me to use in this study. <i>[paper-based]</i> 	-
<ul style="list-style-type: none"> ● no 	-

(Table 6.6 Cont'd)

Control group	Evaluation
<ul style="list-style-type: none"> ● That exercise of any kind has some benefits for high blood pressure and diabetes. I have found with a 20 minute walk in the morning, and at night my sugar levels stay more constant. 	****
<ul style="list-style-type: none"> ● I need to re-energize my exercise program, especially pushaways from the table. 	***
<ul style="list-style-type: none"> ● You need to be sure that the source is credible. 	*/-
<ul style="list-style-type: none"> ● Have trouble finding websites that contain complete information about my condition - either they are not detailed enough and too medical for me to understand 	- -
<ul style="list-style-type: none"> ● Improving one's health takes long-term dedication just like any other goal. 	*
<ul style="list-style-type: none"> ● No. I had done most of my reading before beginning this study. 	0
<ul style="list-style-type: none"> ● Nothing/ No/ Not much/ Nothing I remember[paper-based] (4) 	0
<ul style="list-style-type: none"> ● To look for more information, talk to my doctor or pharmacy. 	*/-
<ul style="list-style-type: none"> ● I have taken this medication for a long time, and so have felt little need for more information. I do occasionally look for information on medications that are new. 	*/-
<ul style="list-style-type: none"> ● Zocor has been linked to memory loss 	- -
<ul style="list-style-type: none"> ● I not been on web seeking information about my health problems. 	0
<ul style="list-style-type: none"> ● How the heart works, stent types, CAD treatments. 	***
<ul style="list-style-type: none"> ● The Internet is too much of a bother, I get tired of paying for virus scan software that ends up interfering with my ISP access 	N/A
<ul style="list-style-type: none"> ● I not been on web seeking information about my health problems. 	0

*Stated as reported.

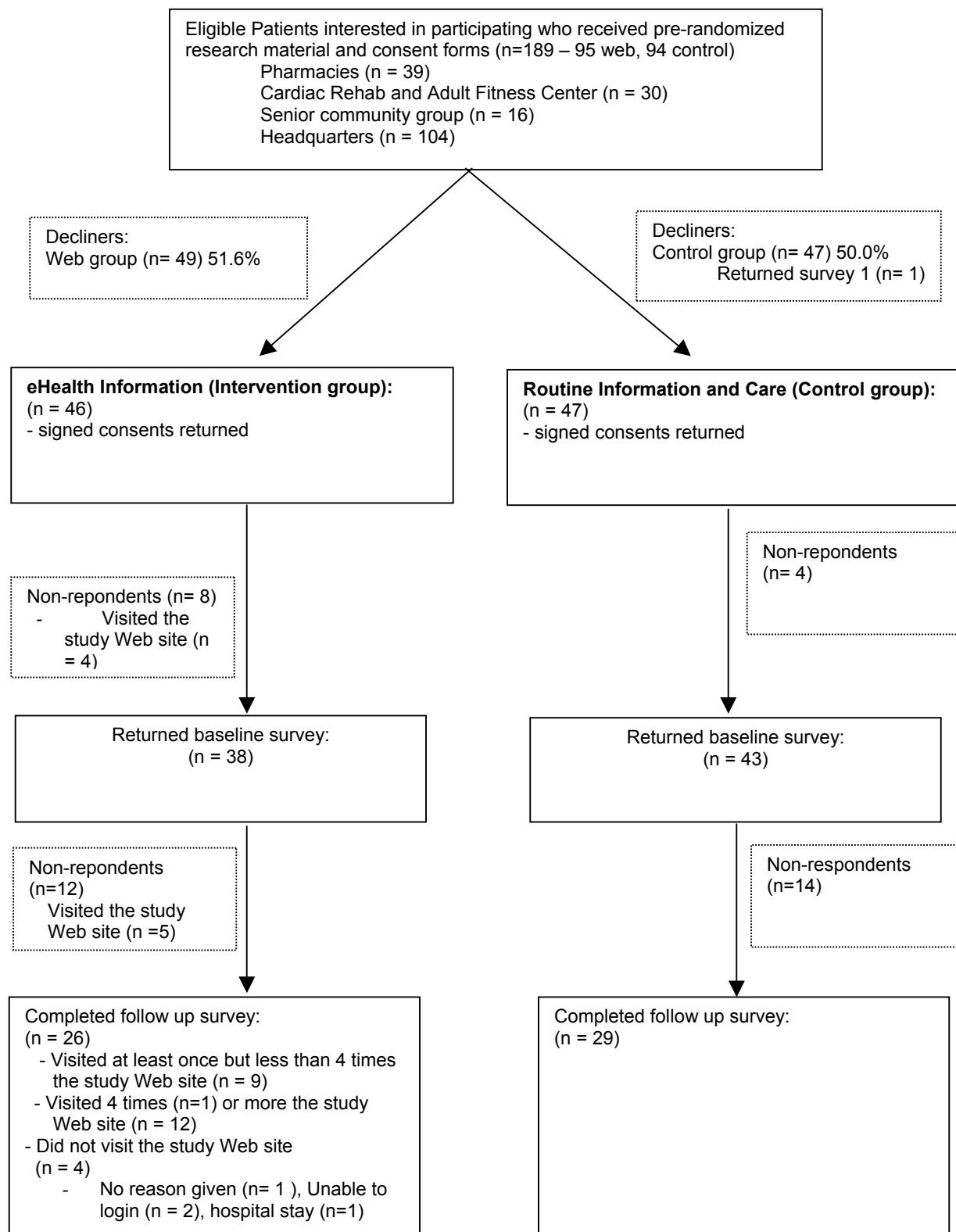


Figure 6.1 Flow chart

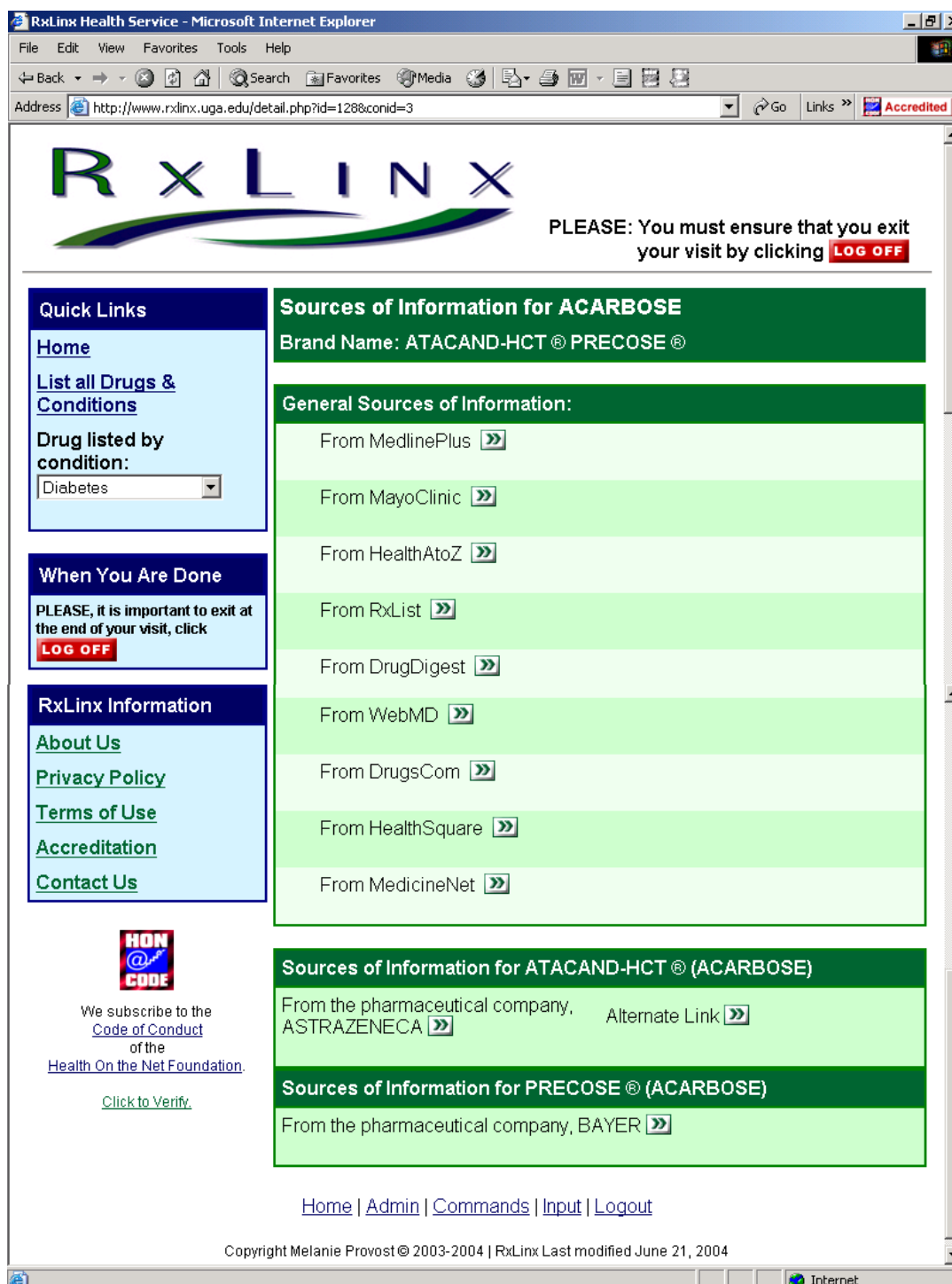


Figure 6.2 Example of a Medication Specific Web Page in the RxLinX .org Study Web Portal

Note: All links of general sources of information were randomly reordered when the user refreshed a page. Brand names mentioned are the properties of the respective companies.

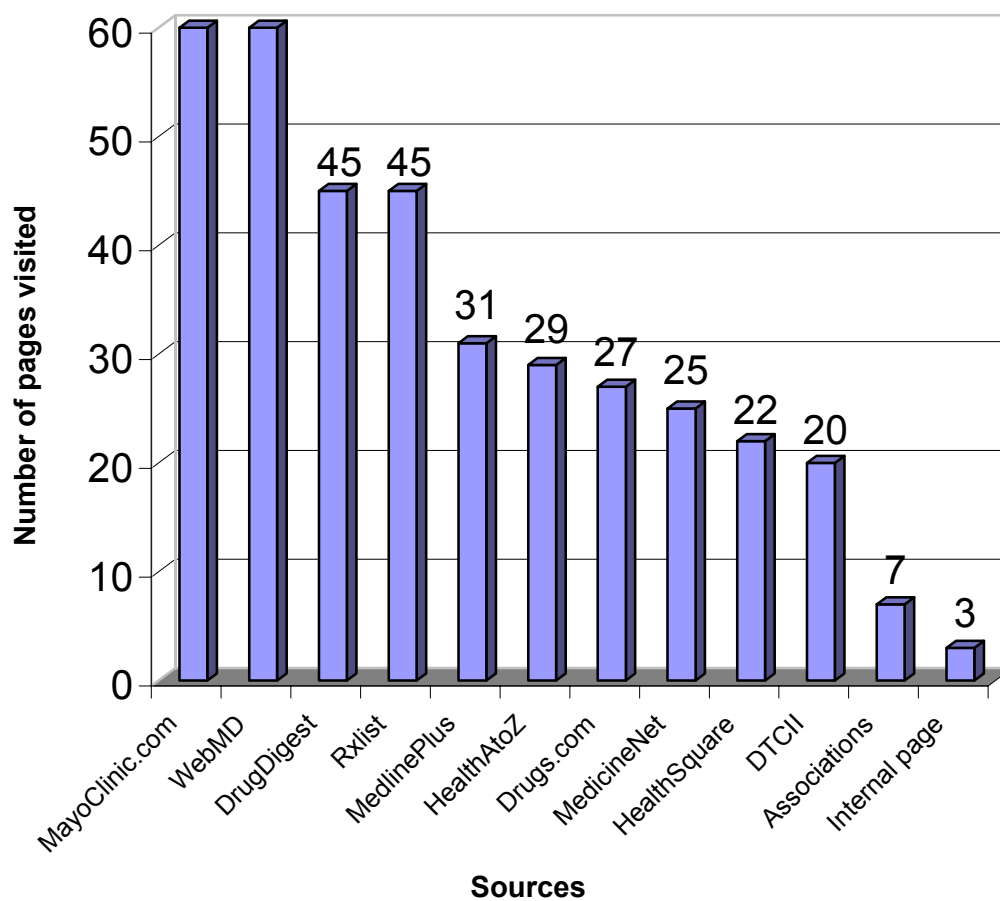


Figure 6.3. Frequency of Selection of Web Links per Source.

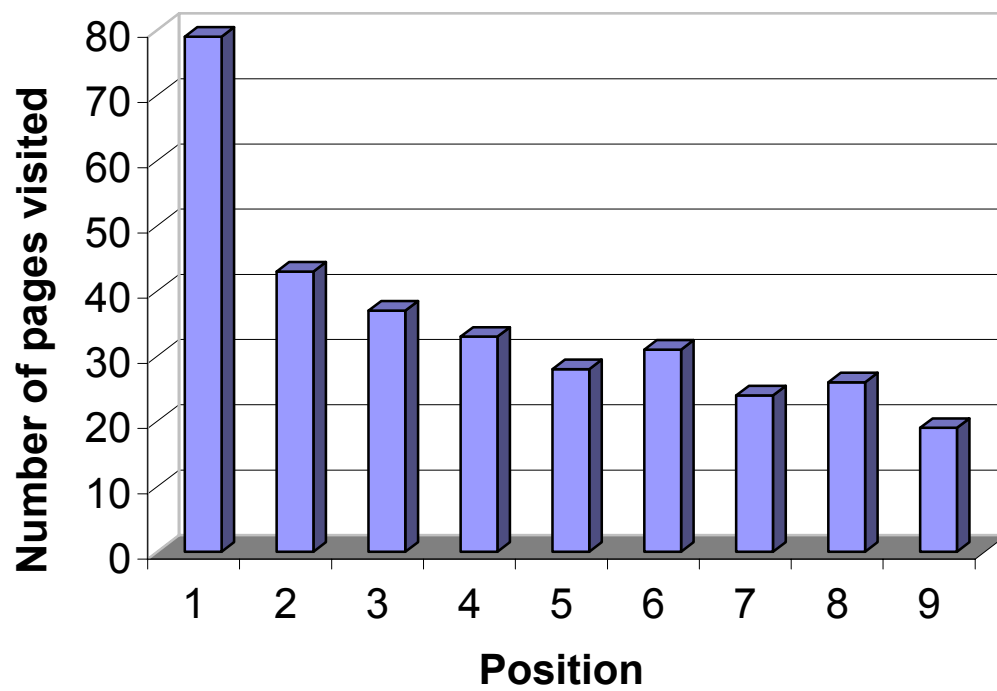


Figure 6.4. Frequency of Selection of Web Links According to the Order of Presentation.

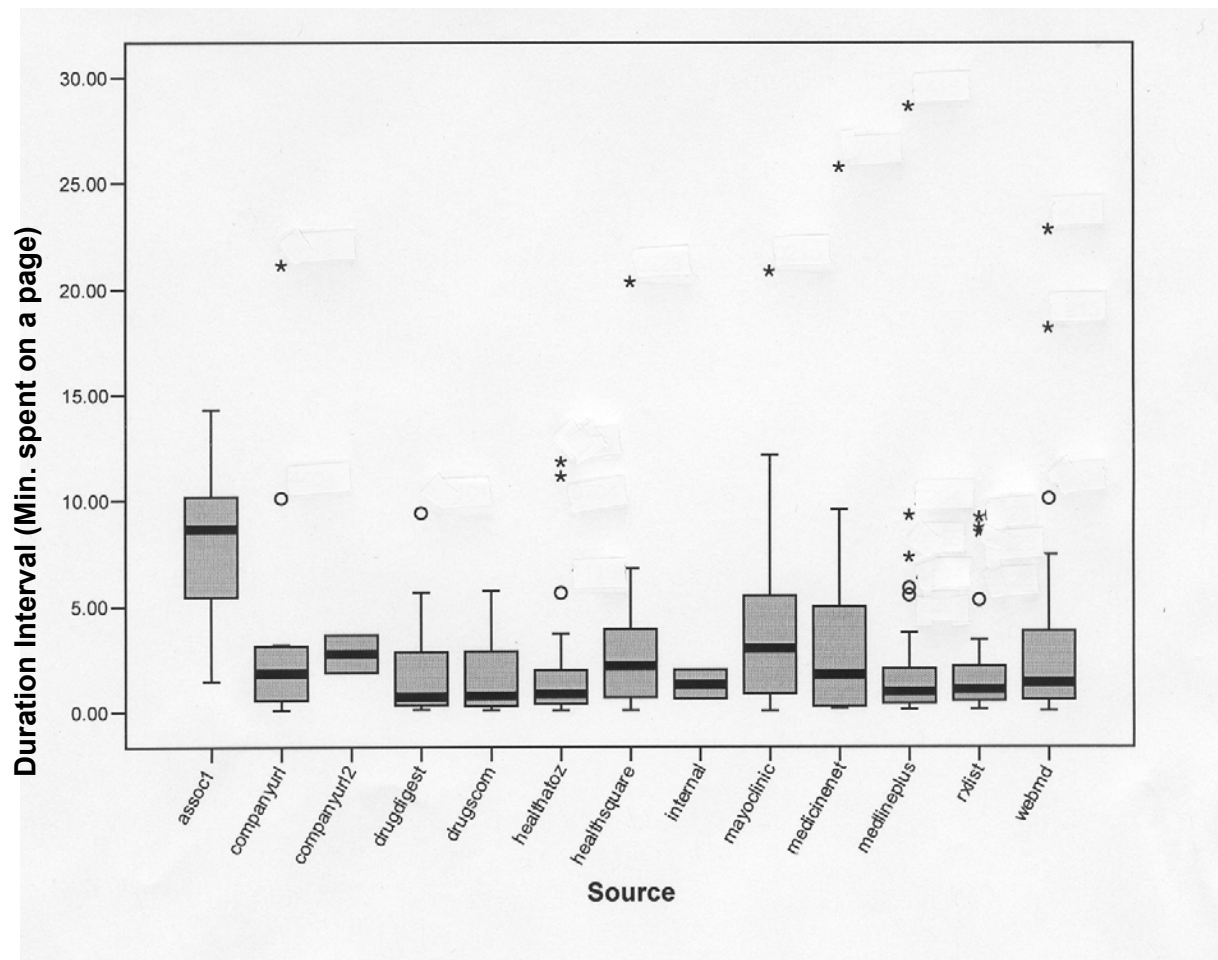


Figure 6.5. Time Spent (Min.) per Source* (n=308 Web pages)

*One outlier deleted (duration >50 min.). There were 65 hits with missing duration.


Multimedia Supplement: Screenshots of the RxLinx.org Web Portal

RxLinx Health Service - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Back Forward Stop Home Search Favorites Media

Address <http://www.rxlinox.uga.edu/> Go Links




Login to RxLinx:


Enter your username:

Enter password:

For questions regarding login,
contact Melanie Provost at provostm@mail.rx.uga.edu or call (706) 296-5668



The University of Georgia
College of Pharmacy
Athens, Georgia, U.S.A




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This site is better viewed for use with Netscape 7.0+ or Microsoft Internet Explorer 5.0+, Screen resolution: 800 x 600 pixels

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Done Internet

Address <http://www.rxlinox.uga.edu/main.php> Go Links



PLEASE: You must ensure that you exit your visit by clicking **LOG OFF**

Welcome to RxLinx

Thank you for choosing RxLinx that provides you with all the essential information for your medication.
If you need assistance with using RxLinx [click here](#).


Find a drug name listed by condition:

- High Blood Pressure
- High Cholesterol
- Diabetes
- Rheumatoid Arthritis

or

Find a drug name in the alphabetical list:

ABCDEFGHIJKLMNOPQRSTUVWXYZ



We subscribe to the [Code of Conduct](#)
of the [Health On the Net Foundation](#).
[Click to Verify](#)

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Internet

RxLinX Health Service - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Back Forward Stop Search Favorites Media RSS Print Mail Print Mail

Address http://www.rxlinx.uga.edu/list.php#a Go Links

R x L I N X

PLEASE: You must ensure that you exit your visit by clicking **LOG OFF**

Quick Links

[Home](#)

[List all Drugs & Conditions](#)

Drug listed by condition:

When You Are Done

PLEASE, it is important to exit at the end of your visit, click **LOG OFF**

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[Accreditation](#)

[Contact Us](#)

High Blood Pressure, High Cholesterol, or Diabetes
General Information about [High Blood Pressure](#), [High Cholesterol](#), [Diabetes](#), [Rheumatoid Arthritis](#)

List of Medications
Find the name of your medication in the following list

Click a letter to jump to the drug:
[A](#)[B](#)[C](#)[D](#)[E](#)[F](#)[G](#)[H](#)[I](#)[J](#)[K](#)[L](#)[M](#)[N](#)[O](#)[P](#)[Q](#)[R](#)[S](#)[T](#)[U](#)[V](#)[W](#)[X](#)[Y](#)[Z](#)

A

[ACARBOSE](#)

[ACCUPRIL ® \(QUINAPRIL HYDROCHLORIDE\)](#)

[ACEBUTOLOL HYDROCHLORIDE](#)

[ACEON ® \(PERINDOPRIL ERBUMINE\)](#)

[ACTOS ® \(PIOGLITAZONE\)](#)

[ADALAT CC ® \(NIFEDIPINE\)](#)

[ADVICOR ® \(NIACIN; LOVASTATIN\)](#)

[ALDACTAZIDE ® \(HYDROCHLOROTHIAZIDE; SPIRONOLACTONE\)](#)

[ALDACTONE ® \(SPIRONOLACTONE\)](#)

[ALDOCLOR-150 ® \(CHLOROTHIAZIDE; METHYLDOPA\)](#)

[ALDOMET ® \(METHYLDOPA\)](#)

[ALDORIL 15 ® \(HYDROCHLOROTHIAZIDE; METHYLDOPA\)](#)

[ALTACE ® \(RAMIPRIL\)](#)

[AMARYL ® \(GLIMEPIRIDE\)](#)

[AMILORIDE](#)

[AMILORIDE](#)

[AMILORIDE HYDROCHLORIDE; HYDROCHLOROTHIAZIDE](#)

[AMLODIPINE BESYLATE](#)

[AMLODIPINE BESYLATE; BENAZEPRIL HYDROCHLORIDE](#)

[ANAKINRA](#)

[APRESOLINE ® \(HYDRALAZINE HYDROCHLORIDE\)](#)

[AQUATENSEN ® \(METHYLCLOTHIAZIDE\)](#)

[ARALEN ® \(CHLOROQUINE\)](#)

[ARAVA ® \(LEFLUNOMIDE\)](#)

[ASPIRIN](#)

[ATACAND ® \(CANDESARTAN CILEXETIL\)](#)

[ATACAND-HCT ® \(ACARBOSE\)](#)

[ATENOLOL](#)

[ATENOLOL; CHLORTHALIDONE](#)

[ATORVASTATIN](#)

[ATROMID-S ® \(CLOFIBRATE\)](#)

[AVALIDE ® \(HYDROCHLOROTHIAZIDE; IRBESARTAN\)](#)

[AVANDAMET ® \(METFORMIN; ROSIGLITAZONE\)](#)

[AVANDIA ® \(ROSIGLITAZONE MALEATE\)](#)

[AVAPRO ® \(IRBESARTAN\)](#)

[AZATHIOPRINE](#)

[AZULFIDINE ® \(SULFASALAZINE\)](#)

B

[BAYCOL ® \(CERIVASTATIN\)](#)

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[BENAZEPRIL HYDROCHLORIDE; HYDROCHLOROTHIAZIDE](#)

[BENDROFLUMETHIAZIDE](#)

[BENDROFLUMETHIAZIDE; NADOLOL](#)

[BENICAR ® \(OLMESARTAN\)](#)

[BENICAR-HCT ® \(HYDROCHLOROTHIAZIDE; OLMESARTAN\)](#)

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- From MayoClinic >>
- From MedicineNet >>
- From WebMD >>
- From RxList >>
- From HealthSquare >>
- From DrugDigest >>
- From DrugsCom >>
- From HealthAtoZ >>

Sources of Information for ATACAND-HCT ® (ACARBOSE)

- From the pharmaceutical company, ASTRAZENECA >> Alternate Link >>

Sources of Information for PRECOSE ® (ACARBOSE)

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Information about High Blood Pressure

This page presents you hyperlinks to sources of information about the disease

Tips: search also your drug in the list all drug names on the left-side menu

General Sources of Information:

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From HealthSquare >>

From MedlinePlus >>

From MayoClinic >>

From MedicineNet >>

From DrugsCom >>

From RxList >>

From HealthAtoZ >>

From DrugDigest >>

Information from Associations:

American Heart Association >> Medem >>

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ADVANCED SEARCH July 9, 2004

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Diseases & Conditions

High Blood Pressure

About High Blood Pressure

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Why Should I Care?

What Can I Do?


Treatment Decision Help

For Professionals

Survivor Feature

High Blood Pressure

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CHAPTER 7

OPINIONS AND EHEALTH BEHAVIOURS OF PATIENTS AND HEALTH PROFESSIONALS IN THE U.S.A. AND EUROPE¹

¹ Provost^{a,b} M., Perri^b III, M., Beaujard^a, V., Boyer^a, C. 2003. *Studies in Health Technology and Informatics*. 95: 695-700. ^aThe Health On the Net Foundation, Switzerland, www.hon.ch;
^bCollege of Pharmacy, The University of Georgia, U.S.A. Reproduced with permission of the publisher.

Abstract

Background: There exists a gap in the use of Internet for health purposes between patients and health professionals and between various countries. The Internet has the potential to be a global tool for health professionals and their patients but, as seen in other fields, cultural differences may lead to divergent opinions and preferences. **Objective:** To identify the opinions, preferences and types of behaviours regarding the use of Internet for health purposes, for health professionals and patients in selected regions of the United States and Europe. **Methods:** An announcement of an online survey was posted on more than 100 web sites during May and June of 2002. Members of HONnewsletter were also invited via email. The online questionnaire consisted of 28 questions with sections designed specifically for patients or health professionals. Sub-samples of respondents were created based on their geographic location. **Results:** 2621 respondents mainly from the United States (38%, n=984) and Europe (29%, n=739) completed the survey. For the USA, the majority of respondents were patients (68.7%), while in Europe, the majority were health care professionals (63.6%). In both regions, health professionals preferred using medical search tools but patients preferred general search tools. Concerns about the accuracy of information and trustworthiness were shared by all groups. The majority of respondents reported that they preferred certified web sites. The patients from USA (69%) and Europe (47%) have discussed the results of their Internet searches with their doctors, while health professionals are receptive to the discussion and find it helpful. Other e-health behaviours are also reported by both parties. **Conclusion:** Based on the self-reported e-health behaviours noted in this study it appears that the use of the Internet for health purposes is growing in importance to the patient-physician relationship in Europe and the USA.

Key Words: Internet; Medical Informatics; Survey, Online Questionnaire; Patient-Physician Relationship; Europe; United States; Preferences; Opinions; Satisfaction; Health Behavior

1. Introduction

Illness is a worldwide issue. With the advent of new technologies and the Internet, citizens of the world have new resources in fighting disease. Studies performed in Canada and United States (USA) have shown that a gap exists in the use of the Internet between patients and health care professionals [1]. It has been further shown that the use of the Internet for health purposes varies between countries and between patients and health professionals [2-4]. At present, little is known about the difference between countries in the use of the Internet for health purposes or the opinions of patients and practitioners toward health information on the Internet. The objective of this project was to explore the utilisation of health information on the Internet and to examine patients and practitioners attitudes toward health information on the Net in Europe and in the USA.

2. Material and Methods

For the last six years, the Health On the Net Foundation (HON) has performed annual or biannual online surveys on the use of Internet for health purposes. HON online surveys use non-probabilistic sampling methods. The most recent survey (the 8th online questionnaire) was available to complete during May and June 2002. Using this self-administered online questionnaire, available at the HON Web site in both French and English, respondents were invited to answer 21 questions focusing on general health Internet use and demographics. In addition, there were 8 questions dedicated to patients and 7 questions were designed for medical professionals. Announcement of the survey, linked to the online questionnaire, was posted on the HON web site and 100 other health-related web sites¹. The survey was also announced by email to about 4000 HON's newsletter subscribers. Sub-samples of respondents were created based on the location and their responses to either the patients' section or the

¹ <http://www.hon.ch/Survey/Spring2002/support.html>

medical professionals' section. *Perl* programming was used in the computation of survey responses.

3. Results

A total of 2621 worldwide respondents completed the survey. The majority of respondents were from North America (USA 38%, Canada 4%, Mexico 1.5%) with 29% being from Europe. Summary of the results for the worldwide sample is posted online [5]. For the present study, analyses are limited to the European and USA sub-samples containing 739 and 984 respondents respectively. For the USA, the majority of respondents were patients (68.7%) while in Europe, the majority were health professionals (63.6%). The percentages of the different health professions are listed in Table 7. 1(all tables are available online¹).

3.1 Experience with the Internet and Information Seeking Behaviour and Preferences

The median length of time a respondent had been using the Internet was 4 to 6 years. More than 60% of patients (USA and Europe) have used the web for more than 4 years. USA professionals seem to have more experience with the Internet than patients, with 37% of this group have used the Internet for more than 7 years and 31% have used it for 4 to 6 years. This compares to only 23% of European professionals having used the Internet for more than 7 years and 38% having used the Internet for 4 to 6 years.

For health professionals in Europe and USA, the most common information sought via the Internet was medical literature, 89.4% and 90.6% respectively (online Table 7. 2). There was also significant interest in disease descriptions (57.2% and 65.9% respectively) and clinical trials (50.2% and 39.9% respectively). Consistent with their purpose, support groups were more commonly looked at by patients (Europe 30.1%, USA 27.8%). It should be noted that patients in

¹ http://www.hon.ch/Survey/Spring2002/Tables1-6_Professionals_Patients-USAvsEurope.html

the USA consulted medical literature to a greater extent (81.5%) than in Europe (60%). Health professionals in both the USA and Europe preferred to use medical search tools (43% and 55%, respectively) to the general search engines (32% and 29%). Patients, however, preferred using general search tools (39% USA, 57% Europe) to medical search tools (29% USA, 23% Europe) (online Table 7. 3). It is possible that the complexity of medical search tools could discourage patients from using these search engines.

3.2 Patients e-Health Behaviour

A summary of the results of patients' e-health behaviours is presented in Table 7. 4. Respondents from the USA are more likely to have discussed information from the Internet with their doctors, with 69% indicating having discussed information from the Internet with their doctors. This shows a large increase over previously reported results [3] which have indicated only about 38% discussed this information with their physician. The European respondents in this sample used email with their health care provider in a similar proportion (19.3%) as USA respondents (21.3%). Given the prevalence of online pharmacy in the USA, perhaps due to regulations and market demand for online shopping, it seems consistent that the proportion of USA-patients (17.16%) buying online medications is more than five times larger than the percentage of Europeans (3.4%) (Online Table 7. 4). Among online buyers, the majority of those from the USA bought prescription drugs (69.6%) while the majority of Europeans bought over-the-counter drugs (57.1%). The only behaviour seen in a greater proportion among the Europeans over the USA-respondents was "seeking of a second opinion on medical diagnosis". Europeans indicated seeking a second opinion in 56.1% of respondents compared to 42.6% in the USA.

Regarding the search behaviours of patients, 75.3% of the USA respondents and 66.2% of European respondents are "seeking information from medical professional sites, or sections

dedicated to medical professionals". Potential benefits or risks related to this e-health behaviour will be discussed in a later section of this paper (see Discussion). More than three out of four people giving a reason for this type of searching behaviour reported a preference for having access to more complex information (78.5%, n=669). Almost half of these respondents (45.3%) reported they access these medical professional sites because the information they access on consumer sites is usually too basic. Respondents were also asked to identify potential solutions to not understanding the information they read on Internet sites. For Europeans and USA respondents, 23.9% (n=155) and 33.2% (n=473), respectively, reported they would "ask their physician". Another solution selected by a very high proportion of patients, 87.5% (USA) and 89.0% (Europe), was to "do alternative searches to clarify the information".

3.3 Health Professionals' e-Health Behaviours

Health professionals from the USA reported having patients discuss health information they have found online with them (81.2%) in a greater proportion than professionals in Europe (63.2%) (online Table 7. 5). However, as noted for the patients, more European professionals engage in email correspondence with their patients (50.0%) than USA (43.5%). Most physicians in Europe (81.9%) and the USA (86.7%) reported using web sites to search for information on drugs. More than half of all physicians in both geographic regions reported recommending web sites to their patients. Support groups and discussion lists were also recommended frequently to patients (Table 7. 4-5). Of physicians whose patients had discussed healthcare information they found on the web with them, the majority (75% to 85% of those with an opinion) indicated that this discussion was helpful: increasing communication, creating more knowledgeable patients, making patients better partners, and making consultation more constructive.

3.4 Respondents' Opinions Regarding Accreditation of Medical Web sites

Respondents reported favourable attitudes toward the certification and/or accreditation of medical web sites. This was demonstrated by their opinions on the effect of certification to reduce the most critical issues listed in the questionnaire. The three most critical issues facing the medical Internet were reported to be accuracy of information, trustworthiness, and ability to find information (10% to 36% of patient and professional respondents in both the USA and Europe). The European professionals have the largest proportion positively supporting the accreditation as a solution to resolve some issues (75.74%) compared to the other groups (up to 66.5%). Awareness of the certification, accreditation, or trust mark systems varies between the different systems: proportions of people familiar with them range from 1.9% to 64.3%. The most familiar accreditation system was the HONcode recognised by 64.3% of health professionals in Europe and 48.05% in USA as well as almost half of patients. The Good HouseKeeping certification program was also familiar to respondents from USA (53.6% of patients; 48.1% of professionals). The accreditation system known by approximately 20 % of USA respondents is the Trust-e. Trust-e is less well-known in Europe, with only about 10% indicating awareness. The NetScoring and URAC, respectively developed and implemented in Europe and USA, were the least familiar to respondents. Because a non-response to these awareness questions could mean that respondents are not familiar with any of the proposed choices, the large proportion of patients (21.3% USA; 38.26% Europe) and health professionals (16.2% USA; 29.2% Europe) who did not respond to these items is of interest. These results may suggest a greater awareness of accreditation systems among USA citizens than European. To evaluate the impact of the various systems of accreditation and certification, respondents were asked if they 'advantage' the certified web sites among those they visited (online Table 7. 6). Almost 2 out of 3 European health professionals (61.9%) and a majority of their colleagues

from USA (55.5%) 'advantage' certified web sites. This same trend was found for the majority of patients (57.8% USA, 54.3% Europe).

4. Discussion

It has been estimated that 14 million of people in France (24% of adults online) and 110 million people in the USA (53% of adults online) have at least looked once for health information on the Internet, while 19% and 26% of them respectively do it often [2]. Respondents in this study reported a high level of experience with the use of the Internet which may not be representative of the global population using the Internet for health purposes. However, this group is of interest because of their significant exposure to various health web sites. In particular, these respondents are valuable since the ways their behaviours have been shaped by the health Internet can be assessed. Additionally, their opinions about the credibility of health Internet content are also valuable, due to their extensive experience with this information source.

Three main observations can be extracted from this descriptive study. First, to a greater extent in the USA but also in Europe, the use of the Internet for health purposes is an important and growing part of the patient-physician relationship. Patients are asking their doctors about information gathered from the health Internet. These physicians are generally receptive in discussing the information found online with their patients. Based on this finding, it may be concluded that the use of the Internet intervenes in shaping the patient-physician relationship. Whether these changes are positive and impact patient health, outcomes needs to be assessed. The evidence from this study seems to support the premise that the patient-physician relationship is being modified in a constructive manner by the health Internet. These trends are mostly observed in USA but also significant in Europe. Considering differences between health care systems, patients in each location may have developed different habits and

involvement levels with respect to their health care. For example, regulations in the USA allowing direct-to-consumer advertising (DTCA) of prescription drugs may have encouraged patients to be involved in the choice of medication through a request to their doctor. This behaviour is much less frequent in countries of Europe where DTCA is not as prominent, and in some cases prohibited. Therefore, one may expect to see differences in the impact of using the Internet for health information on the patient-physician relationship in these two geographic areas. According to the Harris Interactive, USA-citizens are more likely to have discussed with their doctors the information found on the Internet (38%) compared to German, French and Japanese [3]. The present study demonstrated a greater proportion of USA patients who have discussed healthcare information from the Internet with their doctor (69%).

The percentage of health professionals (63%-81%) reporting that patients discuss health care information found online is lower than the ratio previously reported in a cancer centre in Canada where 90% or more of physicians and nurses reported that patients had brought them information from the Internet [1]. The difference may be explained by the difference in medical specialty and the importance of the diagnoses, or potentially by the location of respondents. Of physicians whose patients had discussed healthcare information they found on the web with them, the majority indicated that this discussion was helpful: increasing communication, creating more knowledgeable patients, making patients better partners, and making consultation more constructive. The latter being consistent with the results from a survey of web-using physicians, performed in United Kingdom (UK), indicate that UK-doctors reported more often benefits than harms from the use of Internet by their patients, but for doctor themselves it creates more problems than benefits [6]. Considering the results of the European group, it seems that the Internet is used as a medium of communication with their doctors but are barely performing e-commerce purchases at online pharmacies. The reasons for more than 50% of Europeans to seek a second opinion on medical diagnosis compared to a lower proportion of USA

respondents are unclear. However, this e-health behaviour expresses a desire for greater involvement of European patients in their health care decisions making.

Second, health professionals and patients have concerns regarding the accuracy of the information found online and its trustworthiness. Concerns about the reliability of health information online have been reported; only 20% of UK-physician believes that the information is usually reliable while 48% and 39% respectively answered that it was sometimes reliable and sometimes unreliable [6]. Respondents believe that accreditation and certification systems may contribute to reduce the issues. The majority of health professionals from USA and their patients as well as those from Europe and up to 61.9% of European health professionals reported that they advantage certified sites within the one visited. Third, it seems that patients are seeking more complex information and search for medical scientific literature and sections dedicated to health professionals, but are using mostly general search tools. A paternalistic belief by health professionals would raise concerns for misinterpretation by patients. If patients are confused, do not trust or can't find needed information, the health Internet may not be providing the beneficial effects discussed above. However, based on this study it appears that consumers seem to take actions to increase search activity and question health professionals when they do not understand the information they found.

4.1 Limitations of the study:

Even though more than 100 web sites were employed in this study, voluntary participation could have still provided selection bias. Further, some web sites recruited more respondents than others and this might also have influenced the results. Also, differences observed between the groups of professionals from the USA and from Europe may be explained by other confounding characteristics not included in this study.

4.2 Future Research

Future research should examine where (web site types, geographical locations, web sites) Europeans look when they are searching for a 2nd opinion. This research could also identify the types of behaviours, their frequency and impact on medical practices and patients worldwide. More research is also needed to increase our understanding of which information consumers will use and how it will influence their behaviour. The impact of this information on the patient physician relationship should also be examined for its potential to influence health behaviours and outcomes. Finally, economic analyses should be undertaken to evaluate the cost effectiveness of the Internet as an information source.

5. Conclusions

Because of its global status, the Internet is being used for health-purposes by citizens around the world. Special attention must be given during non-random sampling online questionnaires when seeking opinion or behaviours of individuals since they may come from any countries and can be health professionals or not; both characteristics may influence the results. Health and Internet researchers should consistently report geographic locations of respondents and the source of recruitment when citing research. This will allow for more direct comparison of results and provide for more meaningful analyses and comparisons of results. As we partner in building knowledge on the global phenomenon of the use of Internet for health purposes, tremendous benefits may arise for the global community.

Based on the results presented here, contrary to medical professionals, the general public (patients, not medical professionals) has been using general search engines but like to reach more complex medical scientific literature. Therefore, we can suggest that there is a need for either consumer education about existing medical search tools or development of new types of search tools offering the ease of use of general search engines, but also the possibility to

reach scientific medical literature. In addition, more advanced and automated intelligent technical support should be developed in order to guide consumers in the comprehension of more complex content retrieved.

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Supplement: Online tables ¹

Table 7.1 Proportions of Patients and Professional type of Respondents per location.

Type of Respondents	Respondent Origin	
	U.S.A. (n=984)	Europe (n=739)
Patients	68.7%	36.4%
Professionals	31.3%	63.6%
Medical or health:	94.8%, (n=292)	96.2%, (n=452)
- General Practice	8.56%	19.03%
- Medical Specialty	18.84%	46.68%
- Pharmacist	2.5%	2.88%
- Dentists	0.68%	2.66%
- Nurse	27.4%	5.97%
- Paramedical	0.68%	1.77%
- Med./health student	1.71%	1.33%
- Researchers	5.48%	4.65%
- Alternative med.	4.11%	1.33%
- Information Provider	11.3%	5.31%
- Other	18.84%	8.41%

¹ Found at http://www.hon.ch/Survey/Spring2002/Tables1-6_Professionals_Patients-USAvsEurope.html
(Accessed June 15, 2004)

Table 7.2 Search Interests on the Internet¹

Type of Respondents	Mostly, search for...	Respondent Origin	
		U.S.A. (n) %	Europe (n) %
Patients		(n=676)	(n=269)
	Disease Description	68.49	55.76
	Clinical trials	33.14	21.93
	Medical literature	81.51	58.74
	Support groups	27.81	30.11
	Not Sure	5.92	13.75
	No response	3.11	1.86
Professionals		(n=308)	(n=470)
	Disease Description	65.91	57.23
	Clinical trials	39.94	50.21
	Medical literature	90.58	89.36
	Support groups	18.18	16.17
	Not Sure	3.25	4.26
	No response	2.60	2.55

¹ Found at http://www.hon.ch/Survey/Spring2002/Tables1-6_Professionals_Patients-USAvsEurope.html
(Accessed June 15, 2004)

Table 7.3 Preference of Search Tool Type on the Internet¹

Type of Respondents	Respondent Origin	I Prefer the following Internet search tools:		
		General Tool	Medical Tool	No Response/ No Opinion
Patients	U.S.A. (n=676) %	39.2%	28.99%	31.8%
	Europe (n=269) %	57.25%	22.68%	20.07%
Professionals	U.S.A. (n=308) %	32.47%	43.18%	24.35%
	Europe (n=470) %	29.36%	54.89%	15.74%

¹ Found at http://www.hon.ch/Survey/Spring2002/Tables1-6_Professionals_Patients-USAvsEurope.html (Accessed June 15, 2004)

Table 7. 4 Patients and Professionals e-Health Behaviour in Europe and in USA¹

Behaviour ¹	Patients ²		Health Professionals ³	
	U.S.A.	Europe	U.S.A.	Europe
	(n=676) %	(n=269) %	(n=308) %	(n=470) %
Discussion of Internet searches (P2P)	69.1	46.8	81.2	63.2
Discussion on drug information found (P2P)	66.0	41.3	-	-
Use of online medical consultation services	40.8	31.2	-	-
Drug purchase at online pharmacy	17.2	3.4	15.6	3.2
Email correspondence with patient/provider	21.3	19.3	43.5	50.0
Use the web to search drug information	82.5	69.9	86.7	81.9
Use the Internet to seek second opinions on medical diagnoses.	42.6	56.1	-	-
I recommend web sites to my patients	-	-	74.7	56.2
I recommend support group to my patients	-	-	66.9	49.6
I recommend discussion lists to my patients	-	-	34.4	26.6

¹Results presented are the proportions of patients or health professionals who answered “yes” to the statement. The rest have either say “no” or not responded. ²See online Table 7. 4 for patients' results. ³See online Table 7. 5 for professionals.

¹ As presented in the paper format of the article.

Table 7. 5 Patients e-Health Behaviour in Europe and in USA¹

Patients' Behaviour ¹	Respondent Origin	
	U.S.A. (n=676) %	Europe (n=269) %
I have discussed the results of my Internet searches for medical/health information with my care provider(s)	69.08%	46.84%
I discuss the drug information I find with my care provider(s)	65.98%	41.26%
I have used online medical consultation services offered by web sites.	40.83%	31.23%
I buy drugs via online pharmacy services	17.16%	3.35%
- From prescription	69.61%	42.86%
- Over-the-counter (OTC)	30.39%	57.14%
I engage in email correspondence with my own health care provider(s)	21.3% (n=115)	19.33% (n=40)
- Occasionally	88.7%	77.5%
- Frequently	11.3%	22.5%
I use the web to search for information on drugs	82.54%	69.89%
I use the Internet to seek second opinions on medical diagnoses.	42.6%	56.13%

1 Results presented are the proportion of patients who answered "yes" to the statement.

The rest have either say "no" or not responded.

¹ Found at http://www.hon.ch/Survey/Spring2002/Tables1-6_Professionals_Patients-USAvsEurope.html
(Accessed June 15, 2004)

Table 7. 6 Health Professionals' e-Health Behaviour in Europe and in USA¹

Health Professionals' Behaviour ¹	Respondent Origin	
	U.S.A. (n=308) %	Europe (n=470) %
My patients discuss health care information they have found on the Net with me	81.17%	63.19%
I buy drugs via online pharmacy services	15.58%	3.19%
- From prescription	(n=42)	(n=11)
- Over-the-counter (OTC)	71.43%	63.64%
	28.57%	36.36%
I engage in email correspondence with my patients	43.51%	50.00%
- Occasionally	(n=103)	(n=209)
- Frequently	83.5%	81.34%
	16.5%	18.66%
I use the web to search for information on drugs	86.69%	81.91%
I recommend web sites to my patients	74.68%	56.17%
I recommend support group to my patients	66.88%	49.57%
I recommend discussion lists to my patients	34.42%	26.6%

¹ Results presented are the proportion of patients who answered "yes" to the statement.

The rest have either say "no" or not responded.

¹ Found at http://www.hon.ch/Survey/Spring2002/Tables1-6_Professionals_Patients-USAvsEurope.html
(Accessed June 15, 2004)

Table 7.7 Opinions and Behaviours Regarding Accreditation of Medical Web Sites¹

Items	Respondent Type and their Origin			
	Patients		Professionals	
	U.S.A. (n=676) %	Europe (n=269) %	U.S.A. (n=308) %	Europe (n=470) %
Do you think the certification and/or accreditation of medical web sites may reduce the issues [facing the Internet] ² ?				
- Yes	66.12	66.54	64.29	75.74
- No	28.40	27.51	30.84	18.94
- No response	5.47	5.95	4.87	5.32
Which of the certification, accreditations, or trust marks systems below are you familiar with?				
- Good House Keeping	53.55	9.67	48.05	5.11
- HONcode	47.04	49.07	58.12	64.26
- IHC	4.88	5.58	8.12	5.74
- NetScoring	2.37	3.72	2.27	2.77
- Trust-e	18.79	11.9	20.13	6.60
- URAC	6.95	1.86	8.12	2.34
- No Response	21.3	38.29	16.23	29.15
TOTAL:	100%	100%	100%	100%
Within the site you visit, do you advantage the certified ones				
- Yes	57.84	54.28	55.52	61.91
- No	28.11	32.34	26.62	22.55
- No response	14.05	13.38	17.86	15.53

¹ Results presented are the proportions of patients who answered "yes" to the statement.

The rest answered "no" or did not respond.

² worded in the questionnaire as "issues listed above" which referred to the previous questions.

¹ Found at http://www.hon.ch/Survey/Spring2002/Tables1-6_Professionals_Patients-USAvsEurope.html (Accessed June 15, 2004)

CHAPTER 8

CONCLUSIONS

In this dissertation, the readers are presented with three studies related to eHealth information seeking behaviors. Gaps in knowledge were identified as a lack of measures specific to eHealth and the rarity of evidences related to the benefits, risks and influence of the use of eHealth information by patients on their health care and decisions. However, there exist great challenges in doing research in this novel field where innovative approaches, new thinking, and integration of knowledge from other fields need to be done [Eysenbach, 2002; Wilkeman, 2004; Jadad, Delamothe, 2004; Gustafson, Wyatt, 2004].

EHealth evaluations can be done by researchers in medicine and several other fields, including management information system, medical informatics, nursing and pharmacy. However, a closer attention should be given to integrate the evaluation towards clinical applications with the goal of improving patient's care and health outcomes. For this reason, the author chose patient-centered projects. The main project (Chapter 6) focuses on a more precise population of patients who have been diagnosed with a chronic condition and should be taking their medications as prescribed, but is not always the case. In fact, medication non-adherence is a problem to society that costs over \$100 billion a year in the United States, and reduces benefits to patients from medication that were proven effective if taken as prescribed. As previous works relate knowledge, attitude and medication adherence, there was evidence to support the expectation of an effect of eHealth information would affect those outcomes.

As the eHealth field is in its infancy, instruments are needed to investigate ePatients' behaviors. Chapter 5 presented the readers with the first study showing the development of a new instrument assessing the construct of eHealth self-efficacy. This study built foundations

and instruments taken from other fields and previous works in Internet research. One outcome being the testing of the “Personal Health Information Outcomes Expectancy” scale adapted for the health domain that showed good reliability. Another one being the application of scale development to address an overall e-Patient’s attitude measure related to the use of eHealth information. Thus, the “Perceived Impact of using the EHealth information” was evaluated for its internal reliability, and showed support for validity by its correlation with other related constructs.

Also further results pertaining to the relationships between the eHealth self-efficacy construct and eHealth use brought insights on eHealth information seeking behaviors and its evaluation. EHealth self-efficacy was shown significantly related to eHealth Use but not to Internet use in general. Therefore, careful attention is needed as for the specificity of the measures used in eHealth research when defining the population’s level of experience with technology or with eHealth technology.

Limitations of the study were addressed and suggestions for improvement were made in order to contribute to the advancement of knowledge on eHealth behaviors. The existence of instruments with evidences of reliability and validity in assessing constructs such as eHealth self-efficacy should have implications for researchers in the field of eHealth where measurements are missing to better understand eHealth behaviors. Overall, psychometrics and scale development, largely used in older fields such as social sciences, marketing, and psychology,

The second study, presented in Chapter 6, was a randomized controlled trial measuring the impact of eHealth information on patients’ health behaviors (medication adherence), patient-provider relationships), cognitive concepts (knowledge), and attitudes (satisfaction, perceived impact). The complex nature of the intervention and the determination of an adequate control group trigger the detection of effects from eHealth exposure in an experimental trial. Also, the change in the concept of time and space related to Internet technology [Watson et al., 2002]

intervene in the ability to control the exposure of the control group to information treatment in a longitudinal study. This increased risk of contamination reduces the chance of detecting a treatment effect. A paradox exists since there is also a need for longer time frame evaluations to detect a change in eHealth information seeking behaviors, attitudes and cognition, but this would also increase the chance of exposure among the control group in this type of design.

The treatment effect size of the eHealth information was too small to allow the detection of an effect on medication adherence and knowledge in a population of highly educated patients over a short period. However, the qualitative case-reports are findings of clinical importance, detected in a prospective manner, following exposure to eHealth information. The case-reports showed an impact on patient-provider relationship, an increased awareness of adverse drug reactions monitoring and lifestyle changes for reduction in cardiovascular risks. Stronger evidences would be necessary to investigate if this effect is generalizable to other populations of patients.

These types of findings should be of importance to clinicians, Web information providers, pharmaceutical manufacturers, and researchers. Doctors and pharmacists could be helped in two ways by the use of eHealth information by their patients. First, advising and guiding patients to use eHealth information can be supplemental to the health education and drug information clinicians already provide. Second, informed patients may prevent misused of medications or detect medication error before they occur, which may reduce risks of adverse outcomes and liability lawsuits. E-patients are new medical colleagues who could provide sustainable healthcare solutions [Ferguson, Frydman, 2004].

Pharmaceutical manufacturers can gain from the evaluation methodology taken in this study as to evaluate the effect of direct-to-consumer Internet information (DTCII) or brand's Web sites. A medication-specific Web site is more than a "Web presence" in line with the Food and Drug Administration's DTC advertising requirements. By providing accurate and helpful

information about their products, manufacturers can build a direct relationship with patients. The end-results would be the proper use of the medication and early management of adverse reactions. More research is needed to demonstrate the benefits of DTCII, as a subcategory of eHealth information, in order to broaden the access to resources provided by multinational pharmaceutical companies but mostly limited in access with the statement “for U.S. residents only” on most Web resources due to restricted regulations governing the provision of direct-to-consumer information from pharmaceutical industry in most European countries and Canada [Bonaccorso, Sturchio, 2004].

For Web information providers, the eHealth self-efficacy construct is important to understand the behaviors of consumers seeking eHealth information. People with lower self-efficacy will not persevere in using the Web site to find health information. The perception of people towards their ability to seek eHealth information may influence their eHealth behaviors, for example, to visit the Web site on repetitive occasions.

Most of all, eHealth researchers can gain from the methodology, design and results of the projects presented in this dissertation that addressed measurement needs, and provided pilot results in order to guide advancement in eHealth research to further evaluate what is the impact of eHealth information seeking behaviors on patients’ adherence, knowledge, attitudes, and patient-provider relationships.

As of May 15th, 2004, Editors of a special issue on eHealth in the *British Medical Journal* stated their regrets for the lack of submissions on the role of information and communication technologies with the objective of keeping people healthy [Jadad, Delamothe, 2004]. More precisely, they stated a gap in research evaluating whether the use of eHealth information and technology actually improved patient care in practice. The objective of the randomized trial presented in this dissertation addressed part of this gap. Future research can build on several

aspects of the methodology used in this research, and use the results as pilot data for further evaluation of eHealth information seeking.

The author abides by a new eHealth philosophy where challenges are opportunities, and where information and communication technologies are transforming the way health care is provided. ¶

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APPENDICES

APPENDIX A

Hill-Bone Compliance to High Blood Pressure Scale

Medication subscale:

1. How often do you forget to take your [high blood pressure] medicine?
2. How often do you decide not to take your [high blood pressure] medicine?
3. How often do you forget to get your prescription filled?
4. How often do you run out of pills?
5. How often do you skip your [high blood pressure] medicine before you go to the doctor?
6. How often do you miss taking your medicine when you feel sick?
7. How often do you take someone else's [high blood pressure] pills?
8. How often do you miss taking your [high blood pressure] pills when you are careless?

(1) none of the time , (2) some of the time, (3) Most of the time, (4) All of the time

Chronbach's alpha of Hill-Bone scale: 0.85 (study one), 0.74 (study two)

The total scale has 14 items. The two other sub-scales assess sodium intake and appointment adherence.

Reference: Kim MT, Hill M, Bone L, Levine D. Development and Testing of the Hill-Bone Compliance to High Blood Pressure Therapy Scale. Progress in Cardiovascular Nursing 2000; 15:90-6.

Appendix B

Personal Information Outcome Expectancy ($\alpha = 0.83$)

7-very likely to 1-very unlikely

- Find current information like time, weather, stock prices and sports scores;
- Get information about products and services;
- Get immediate knowledge of big news events;
- Get information I can trust;
- Find information that is new to me;
- Encounter controversial information;
- Find information to complete a course assignment.

Reference: Eastin MA and Larose RL. Internet Self-Efficacy and the Psychology of the digital device. *Journal of Computer Mediated Communication*, 2000;6(1). URL: <http://www.ascusc.org/jcmc/vol6/issue1/eastin.html> [Accessed July 19, 2004]

This scale was adapted to health information expected outcomes as follow:

1-very unlikely to 5-very likely

- Find current information like health news, new drug discovery, clinical trials, and epidemic outbreaks;
- Get information about medications, devices and health services;
- Get immediate knowledge of big health news events;
- Get health and drug information I can trust;
- Find health information that is new to me;
- Encounter controversial health information;

Appendix C. Implied Consent – Survey Only Group

Subject: UGA College of Pharmacy Project - eHealth

Dear [Mr./Ms. NAME],

A few days back you indicated via email that you may be interested in participating in our Internet & Health project entitled “eHealth information in pharmacy” Thank you for your response! Unfortunately, you do not meet all of the inclusion criteria for the “eHealth information in pharmacy” study because you do not currently take a prescription medication for high blood pressure, diabetes and/or high cholesterol. But, you can still help with the research:

CONSENT AND SURVEY ACCESS:

The “eHealth information in pharmacy” is being conducted to better understand how consumers use the Internet for obtaining health or medication information. The results of this research will assist health professionals and researchers in understanding the use of the Internet related to health care.

Your participation is voluntary. No risk, stress or discomfort is expected as a result of taking this survey.

The online survey takes about 15 minutes to complete. If you decide to take this survey, you can access it using the following information:

To get started, please click on the following link: [SURVEY_LINK_NO_LOGIN]

If for any reason this link doesn't work in your system, you may use the following:

your respondent ID: [RESP_LOGIN_NAME]

your password: [RESP_PASSWORD]

by clicking on the following link: <http://www.rxlinx.uga.edu/survey/>

If you prefer to do it at home, you can print this page to have the information with you.

By agreeing to participate, you will be provided access to the project Web site for 6 months at the end of the study. This token of appreciation has no monetary value. Your participation is important to better understand why millions of Americans use the Internet to get health information. I also personally appreciate your help by participating to my doctoral project!

If you decide to take this survey, you acknowledge that:

-As you know, Internet communications are insecure and there is a limit to the confidentiality that can be guaranteed due to the technology itself.

-Any information the researchers obtain about you in this study, including you identity and email address, will be held confidential. No information about you, or provided by you during the research, will be shared with others (including your employer) without your written permission, except if it is required by law. All data will be kept in a secured, limited access location. Your identity and your employer will not be revealed in any publication of the results of this research.

Please help us to maximize our response rate, and take a few moments to answer the survey today. If you do not want to participate, simply ignore this message. For questions or comments

about this study, please feel free to call me at (706) 296-5668, or my professor, Dr. Matthew Perri III, at (706) 542-5365. Or you may send us an email at the addresses below.

To get started, please click on the following link: [SURVEY_LINK_NO_LOGIN]

If for any reason this link doesn't work in your system, you may use the following:

your respondent ID: [RESP_LOGIN_NAME]

your password: [RESP_PASSWORD]

on this site <http://www.rxlinx.uga.edu/survey>

Thank you very much for your participation!

Sincerely,

Melanie

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Athens, GA 30602-2354
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Matthew Perri, RPh, Ph.D. (Major Advisor)
Clinical & Administrative Pharmacy
College of Pharmacy
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Athens, GA 30602-2354
Tel: (706) 542-5365
Email: mperri@rx.uga.edu

Additional questions or problems regarding your rights as a research participant should be addressed to Chris A. Joseph, Ph.D. Human Subjects Office, University of Georgia, 606A Boyd Graduate Studies Research Center, Athens, Georgia 30602-7411; Telephone (706) 542-3199; E-Mail Address IRB@uga.edu

CONFIDENTIALITY NOTICE: This email communication and any attachments may contain confidential and privileged information for the use of the designated recipients named above. Distribution, reproduction or any other use of this transmission by any party other than the intended recipient is prohibited.

Do not distribute or forward this message without expressive agreement from its author.


Appendix D Cross-Sectional Questionnaire – Survey Only (Online version)

phpSurvey - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Back Forward Stop Search Favorites Media Print View Source

Address http://www.rxlinc.uga.edu/survey/ Go Links »



phpSurvey

RespondentLogin

Respondent ID

Password


[Forgotten your password?](#) | [Admin Login click here.](#)

Best Viewed With
Any Browser

Done Internet

Back Forward Stop Search Favorites Media Print View Source

Address http://www.rxlinc.uga.edu/survey/ Go Links »



Online survey System
phpSurvey

Main Menu

- [Home](#)
- [Modify Personal Details](#)
- [Logout](#)

Welcome, Mel

The list below detailing surveys you need to fill out.
Click on the **Display** link on the most right column in order to display the survey.

Available surveys Search in

ABCDEFGHIJKLMNOPQRSTUVWXYZ 0123456789 - All

No	Survey ID	Title	Anonymous	Submission status	Closing time	
1	37		No	Unfilled	2004-07-14 22:00:00	Display
2	44		Yes	Unfilled	2004-07-14 12:00:00	Display

©2003-2004, phpSurvey


Done Internet

phpSurvey - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Back Forward Stop Home Search Favorites Media Print Mail News RSS Feeds

Address <http://www.rxlinx.uga.edu/survey/> Go Links



Main Menu

- Home
- > Filling-in survey
- Modify Personal Details
- Logout

<-- Hide Nav Bar

Survey type: **Anonymous**
★ indicates required field

Submit Suspend/Save Reset

Scroll down to read the cover letter. The survey follows. Do not press the above buttons yet; scroll down the page to begin the survey.

CONSENT LETTER
The project titled *eHealth information in pharmacy* is being conducted to better understand how consumers use the Internet for obtaining health or medication information. The results of this research will assist health professionals and researchers in understanding the use of the Internet related to health care.

Your participation is voluntary. No risk, stress or discomfort is expected as a result of taking this survey.

The online survey takes about 10 minutes to complete.

By agreeing to participate, you will be provided access to the project Web site for 6 months at the end of the study. Your participation is important to better understand why millions of Americans use the Internet to get health information. I also personally appreciate your help by participating to my doctoral project!

If you decide to take this survey, you acknowledge that:
-As you know, Internet communications are insecure and there is a limit to the confidentiality that can be guaranteed due to the technology itself.
-Any information the researchers obtain about you in this study, including your identity and email address, will be held confidential. No information about you, or provided by you during the research, will be shared with others (including your employer) without your written permission, except if it is required by law. All data will be kept in a secured, limited access location. Your identity and your employer will not be revealed in any publication of the results of this research.

Please help us to maximize our response rate, and take a few moments to answer the survey today. If you do not want to participate, simply close this window browser. For questions or comments about this study, please feel free to call me at (706) 296-5668, or my professor, Dr. Matthew Perri III, at (706) 542-5365.

Thank you very much for your participation!

Melanie Provost, B.Sc. Ph.D. Candidate
Clinical & Administrative Pharmacy
College of Pharmacy, University of Georgia
Tel: (706) 296-5668
Email: provostm@rx.uga.edu

**
Additional questions or problems regarding your rights as a research participant should be addressed to Chris A. Joseph, Ph.D. Human Subjects Office, University of Georgia, 606A Boyd Graduate Studies Research Center, Athens, Georgia 30602-7411; Telephone (706) 542-3199; E-Mail Address IRB@uga.edu
**

INSTRUCTIONS: using your mouse/pointer, click on a circle to make a black dot appear to select your answer. To change your answer, simply click another circle.

If you want to save your answers and continue later, you can click the suspend/save button. You will need to re-enter the survey page to continue at a later point.

Done Internet

phpSurvey - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Back Forward Stop Home Search Favorites Media Print W

Address <http://www.rxlrx.uga.edu/survey/> Go Links >>

1. About your use of the Internet

- Where do you most often access the Internet for personal searches?
 - ☐ From home
 - ☐ From work
 - ☐ From home and work about equal
 - ☐ From public access places (library or other)
 - ☐ Other
- Which kind of Internet connection do you use most often for personal searches?
 - ☐ Dial-up access (Telephone modem)
 - ☐ High speed, Cable modem, network, LAN or DSL (Digital Subscriber Line)
 - ☐ I don't know
- How long have you been using the Internet?
 - ☐ Less than 6 months
 - ☐ More than 6 months but less than 2 years
 - ☐ 2-4 years
 - ☐ More than 4 years
- How many hours per week do you use the Internet for emailing? *(Click in the box and type your answer)*
 Number of hour(s):
- How many hours per week do you use the Internet other than emailing? *(click in the box and type your answer)*
 Number of hour(s):
- Thinking about the past year, would you characterize yourself as someone who:
 - ☐ Has never looked for health information on the Internet.
 - ☐ Has received Internet health information from a friend or family member but has not looked up health information yourself.
 - ☐ Has looked up health information on the Internet.
 - ☐ I don't know
- How often do you use the Internet to look for advice or information about health?

- ☐ About once a week or more
- ☐ About once a month
- ☐ Every few months
- ☐ Once or twice a year
- ☐ Never (*If you answered "Never", skip the following questions, and scroll down to question 11*)
- ☐ I don't know

8. How much, if at all, has getting health information on the Internet improved the way you take care of your health?

- ☐ A lot
- ☐ Some
- ☐ Only a little
- ☐ Not at all
- ☐ I don't know

9. When was the LAST time you went online to look for advice or information about health or health care?

- ☐ Within the last week
- ☐ In the last month
- ☐ In the last 6 months
- ☐ More than 6 months ago
- ☐ I don't know

10. How much do you agree or disagree with the following statements?

Using the Web to find health information...

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
...I feel I have more power to make decisions about my health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

...can help me talk with my doctor about my health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I feel that getting the information is overwhelming.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...makes me confused as to the right course of treatment for my disease.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...makes me aware of conflicting medical information about my disease and its treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...helps me take better care of my own health.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

11. How much of the health information you see on the Internet do you think you can believe?

- ☐ Almost all
☐ Most
☐ Some
☐ Almost none
☐ I don't know

12. How much do you agree or disagree with the following statements?

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I feel confident using a new health Web site I have never used before.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel confident finding health resources on the Web if the Web site had a Frequently Asked Questions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	(FAQ) section.					
	I feel confident that I could find health resources on the Web if I had someone to call or email if I get stuck.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Working with computer makes me very nervous.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	I feel confident finding health resources on the Web by myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	I get a sinking feeling when I think of trying to use a computer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	I feel confident finding health resources on the Web as long as I have plenty of time to search.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	I feel confident that I could find health resources on the Web using a general search engine (ex.: Google, AOL, Yahoo).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Computers make me feel uncomfortable.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	I feel confident surfing the World Wide Web (WWW)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<p>INSTRUCTIONS: For some questions, you can check more than one box to indicate your answers. To change your selected answer, simply click a second time in the squared box to delete a check mark.</p> <p>13. During the past 2 months, which Web sources of health information did you use? (Select all that may apply)</p> <p><input type="checkbox"/> None</p> <p><input type="checkbox"/> Health specific Web sites (for example, WebMD, Walgreens)</p> <p><input type="checkbox"/> Other Web sites (for example, CNN.com/health, Health.Yahoo.com)</p> <p><input type="checkbox"/> Search engine searches (Google, Yahoo, AOL, MSN, or other)</p>						

14. How likely or unlikely is it for you to use the Web to do each of the following task?

	Very unlikely	Unlikely	Neutral	Likely	Very likely
Find current information like health news, new drug discoveries, clinical trials, and epidemic outbreaks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get information about medications, devices and health services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get immediate knowledge of big health news events	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get health and drug information you can trust	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Find health information that is new to you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Learn about controversial health information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Learn about healthy lifestyles (including nutrition, exercise, prevention)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2. About you

15. What is your gender?

- ☐ Male
- ☐ Female

16. In general, how do you rate your own health?

- ☐ Excellent
- ☐ Good

- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor

17. How old are you?

18. How would you describe yourself?

- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Black or African American
- ☐ Hispanic or Latino
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ White or Caucasian
- ☐ Other
- ☐ I don't know

19. What is your highest level of education?

- ☐ High school or less
- ☐ Some college
- ☐ College graduate
- ☐ Post-graduate studies or professional degree (e.g. Master, Ph.D., MD)

20. What is your annual household income?

- ☐ Less than \$15,000
- ☐ \$15,000 to \$24,999
- ☐ \$25,000 to \$34,999
- ☐ \$35,000 to \$49,999
- ☐ \$50,000 to \$74,999
- ☐ \$75,000 to \$99,999
- ☐ \$100,000 or more
- ☐ I don't know / refuse

3. About your health in general

24. How satisfied are you with the amount of information provided to you at the pharmacy about your medication?

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Neither satisfied nor dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied

25. How satisfied are you with the amount of information provided to you at the pharmacy about your health condition or disease for which you received this treatment?

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Neither satisfied nor dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied

26. For each of the following question, please indicate how often you act as mentioned.

	None of the time	Some of the time	Neutral	Most of the time	All of the time
How often do you forget to take your prescribed medicine?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you decide not to take your prescribed medicine?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you forget to have your prescription refilled?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you run out of pills?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you skip your prescribed medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	How often do you skip your prescribed medicine before you go to the doctor?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	How often do you miss taking your medicine when you feel sick?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	How often do you take someone else's prescribed pills?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	How often do you miss taking your prescribed pills when you are careless?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<p>27. How frequently did you seek information using the Internet about your medication or the health condition it treats since you first received your medication?</p> <p> <input type="radio"/> Very often <input type="radio"/> Often <input type="radio"/> Occasionally <input type="radio"/> Rarely (at least once) <input type="radio"/> Never (If you answered "Never", skip the following questions and scroll down to the end, then submit your survey) <input type="radio"/> I don't know </p>					
	<p>28. How satisfied are you with the information you found online about your prescribed medication?</p> <p> <input type="radio"/> Very dissatisfied <input type="radio"/> Somewhat dissatisfied <input type="radio"/> Neither satisfied nor dissatisfied <input type="radio"/> Somewhat satisfied <input type="radio"/> Very satisfied </p>					

29. How much did the information you found online about your medication cause you to worry about taking your medication?

- ☐ Not at all worried
- ☐ A little worried
- ☐ Somewhat worried
- ☐ Worried a lot

30. How frequently, if at all, did you visit the Web site provided by the company of the prescribed medication you are taking?

- ☐ Very often
- ☐ Often
- ☐ Occasionally
- ☐ Rarely (at least once)
- ☐ Never

Thanks a lot for your help!
When you are done, simply click the submit button.

If you want to save your answers and continue later, you can click the suspend/save button. You will need to re-enter the survey page to continue at a later point.

INSTRUCTIONS

Submit: will send your answers to the researchers

Suspend/Save: will keep your answers so that you can continue later.

Reset: will delete all your answers.

Submit

Suspend/Save

Reset

©2003-2004, phpSurvey

Done

Internet

Appendix E. Consent Form – Control group

ID #####

Participation Consent Form

After reading this consent form, you will decide whether or not you wish to participate in the research project described and sign this consent.

I agree to participate in a research study titled “*eHealth Information in Pharmacy*” that concerns Internet utilization for health purposes. The research is conducted by Melanie Provost, Ph.D. candidate (706-296-5668), under the direction of Dr. Matthew Perri III, pharmacist and professor (706-542-5365). Both are from the College of Pharmacy, Clinical and Administrative Pharmacy, The University of Georgia. I understand that my participation is voluntary. I can stop taking part without giving any reason, and without penalty. I can ask to have all of the information about me returned to me, removed from the research records, or destroyed.

The purpose of this research is to evaluate the usefulness of the Internet for health purposes. In order to make this study a valid one, some people will be asked to visit a study Web site while others will not.

My participation in this project can benefit me. By agreeing to participate, I will be provided a family membership access to the project Web site for 6 months at the end of the study. This token of appreciation has no monetary value. The results can also help health professionals to build programs for millions of Americans who believe that information about prescription drugs is important.

If I volunteer to take part in this research, my participation will involve the following:

1. I will read and complete a *Participation Consent*, an *Authorization to Use & Disclose Health Information form* including the acknowledgement of receipt of Notice of Privacy (first day only, 10 minutes).
2. I will complete a *first questionnaire* about my previous Internet experience and general information about me. It should take me about 5 minutes today or in the next few days.
3. I will be emailed or mailed a confirmation of my participation in this research.
4. The *second questionnaire* will be sent to me by email or mail in about 2 months, and will take me about 15 minutes. I may receive a phone call or email to remind me to complete it.

[If I am among the first 100 people who registered to participate, I will receive a \$10 Home Depot gift-card.]¹

No risk, stress or discomfort is expected from the participation in this research.

As I know, Internet communications are insecure and there is a limit to the confidentiality that can be guaranteed due to the technology itself.

Any information the researchers obtain about me in this study, including my identity, will be held confidential. My identity will be coded with an identifying number and this number will be used

¹ This sentence was only written on forms used at sites where a financial incentive would be offered to the participants.

on all of the questionnaires I fill out. No information about me, or provided by me during the research, will be shared with others (including my employer) without my written permission, except if it is required by law. All data will be kept in a secured, limited access location. My identity and my employer will not be revealed in any publication of the results of this research. My email address will not be used for other purposes than for this project.

I give my permission for the pharmacist to release my medication record information to the researcher.

Circle one: YES / NO. Initial _____. I understand that I will not be able to participate in this research study if I do not agree to disclose this information. I will also sign the separate Pharmacy Release form for my pharmacy and acknowledgment of receipt of the Notice of Privacy.

Dr. Perri (Tel: 706-542-5365, email: mperry@mail.rx.uga.edu) and Ms. Provost (Tel: 706-296-5668, email: provostm@mail.rx.uga.edu) will be happy to answer any further questions about the research, now or during the course of the project by telephone or by email.

I understand that I am agreeing by my signature on this form to take part in this research project and understand that I will receive a signed copy of this consent form for my records.

Melanie Provost, B. Sc., Ph.D. Candidate
Tel: (706) 296-5668

Matthew Perri III, RPh, Ph.D. Date
Tel: (706) 542-5365

Your Name

Signature Date

Your email address*
*if you do not have an email address,
you still can participate in this study.

Your telephone number

Please sign both copies, keep one and return one to the pharmacy staff for the researcher.

Additional questions or problems regarding your rights as a research participant should be addressed to Chris A. Joseph, Ph.D. Human Subjects Office, University of Georgia, 606A Boyd Graduate Studies Research Center, Athens, Georgia 30602-7411; Telephone (706) 542-3199; E-Mail Address IRB@uga.edu
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Appendix F. Consent form – EHealth Intervention Group

ID #####

Participation Consent Form

After reading this consent form, you will decide whether or not you wish to participate in the research project described and sign this consent.

I agree to participate in a research study titled “*eHealth Information in Pharmacy*” that concerns Internet utilization for health purposes. The research is conducted by Melanie Provost, Ph.D. candidate (706-296-5668), under the direction of Dr. Matthew Perri III, pharmacist and professor (542-5365). Both are from the College of Pharmacy, Clinical and Administrative Pharmacy, The University of Georgia. I understand that my participation is voluntary. I can stop taking part without giving any reason, and without penalty. I can ask to have all of the information about me returned to me, removed from the research records, or destroyed.

The purpose for this research is to evaluate the usefulness of the Internet for health purposes. In order to make this study a valid one, some people will be asked to visit a study Web site while others will not. The benefits I will receive from participation include: (1) being provided guided access to Internet resources related to my medication, (2) being active in my health care by seeking information related to my health and medication, (3) feeling informed about my health status.

If I volunteer to take part in this research, my participation will involve the following:

5. I will read and complete an *Participation Consent*, an *Authorization to Use & Disclose Health Information form* including the acknowledgement of receipt of Notice of Privacy (first day only, 10 minutes)
6. I will complete a *first questionnaire* about my previous Internet experience and general information. It should take me about 5 minutes today or in the next few days.
7. I will visit the research Web site named RxLinx.org 4 times over the next 2 months. This site will guide me to health resources to learn about my new medication and disease.
8. I will be emailed or mailed to confirm my participation in this research and to remind me to visit the site.
9. I will be responsible for accessing the Internet by my own means. A personal login and password will be provided to me to access the study Web site free of charge.
10. Researchers will access the web log of what sites I visit from the research Web site.
11. The *second questionnaire* will be sent to me by email or mail in about 2 months, and will take me about 15 minutes. I may receive a phone call or email to remind me to complete it.

By agreeing to participate, I will be provided a family membership access to the Web directory for 6 months. This token of appreciation has no monetary value. [If I am among the first 100 people who registered to participate, I will receive a \$10 Home Depot gift-card.]¹

As I know, Internet communications are insecure and there is a limit to the confidentiality that can be guaranteed due to the technology itself. I understand that I am responsible to read the

¹ This sentence was only written on forms used at sites where a financial incentive would be offered to the participants.

privacy policy of external Web sites and that researchers have not reviewed the content of those sites for accuracy.

No risk, stress or discomfort is expected from the participation in this research.

Any information the researchers obtain about me in this study, including my identity, will be held confidential. My identity will be coded with an identifying number and this number will be used on all of the questionnaires I fill out. No information about me, or provided by me during the research, will be shared with others (including my employer) without my written permission, except if it is required by law. All data will be kept in a secured, limited access location. My identity and my employer will not be revealed in any publication of the results of this research. My email address will not be used for other purposes than for this project.

I give my permission for the pharmacist to release my medication record information to the researcher.

Circle one: YES / NO. Initial _____. I understand that I will not be able to participate in this research study if I do not agree to disclose this information. I will also sign the separate Pharmacy Release form for my pharmacy and acknowledgment of receipt of the Notice of Privacy.

Dr. Perri (Tel: 706-542-5365, email: mperry@mail.rx.uga.edu) and Ms. Provost (Tel: 706-296-5668, email: provostm@mail.rx.uga.edu) will be happy to answer any further questions about the research, now or during the course of the project by telephone or by email (see addresses below).

I understand that I am agreeing by my signature on this form to take part in this research project and understand that I will receive a signed copy of this consent form for my records.

Melanie Provost, B. Sc., Ph.D. Candidate
Tel: (706) 296-5668

Matthew Perri III, RPh, Ph.D. Date
Tel: (706) 542-5365

Your Name

Signature

Date

Your email address

Your telephone number

*If you do not have an email address,
you still can participate in this study.

Please sign both copies, keep one and return one to the pharmacy staff for the researcher.

Additional questions or problems regarding your rights as a research participant should be addressed to Chris A. Joseph, Ph.D. Human Subjects Office, University of Georgia, 606A Boyd Graduate Studies Research Center, Athens, Georgia 30602-7411; Telephone (706) 542-3199; E-Mail Address IRB@uga.edu
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Appendix G Authorization to Use and Disclose Health Information Form

Authorization to Use & Disclose Health Information Form

CONSENT TO THE USE AND DISCLOSURE OF HEALTH INFORMATION AND
ACKNOWLEDGEMENT OF RECEIPT OF NOTICE OF PRIVACY.

Although my health record is the physical property of the healthcare practitioner or facility that compiled it, the information belongs to me. Federal Law provides me the right to: request a restriction on certain uses and disclosures of my information, inspect and obtain a copy of my health records, and authorize use of disclosure of any of my protected health information by using the *Authorization to Use & Disclose Health Information Form*.

By signing this form, I, _____, born on _____(month/day/year) give permission to the pharmacist at the pharmacy named _____, located at _____(address) to disclose my medication information records in order to participate in the research study, *eHealth Information in Pharmacy*, conducted by Melanie Provost and Dr. Matthew Perri III from the College of Pharmacy, at the University of Georgia. This written permission is good only for this one time release of my patient records to the investigators. The privacy of my information will be ensured as stated in the *Participation Consent Form*, as approved by the University of Georgia Institutional Review Board.

I agree that the principal investigator, Melanie Provost, will contact my pharmacist by letter, telephone or in person to receive my medication information in hand or by regular mail.

I understand that this information serves as a basis for understanding patients' needs for information related to their medication and the utilization of medication.

I understand and have been provided with a *Notice of Health Information Privacy Practices* that provides a more complete description of information uses and disclosures. I understand that I have the right to review the notice prior to signing this consent. If I wish to discuss any privacy issues or concerns, I can contact my pharmacist, or contact the Privacy Officer at (706) 542-7400, College of Pharmacy, the University of Georgia.

I fully understand and accept the terms of this consent and acknowledgement of receipt of notice.

Sign 2 copies of this form. One for me; the other is for the research investigators. A photocopy will be made and provided to my pharmacy.

Your Signature

Date

Your telephone number

Witness

Date

Appendix H Notice of Privacy (internal side of leaflet)

<p>UNIVERSITY OF GA COLLEGE OF PHARMACY, RESEARCH PROJECT NOTICE OF HEALTH INFORMATION PRIVACY PRACTICES</p> <p>THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW IT CAREFULLY.</p> <p>Which information is collected?</p> <p>The researchers will respect the confidentiality of all information about you as stated in the Consent Form you signed to participate in this research study.</p> <p>The answers you provide in any questionnaire about your health or opinions, as well as the information about your medication will be kept confidential. This document explains to you how we may share some information among the researchers.</p> <p>In general, each time you visit a Web site, some identifiable information such as your computer's IP address is collected by the Web provider.</p> <p>As you know, internet communications and emails are insecure and there is a limit to the confidentiality that can be guaranteed due to the technology itself. No personal health information should be shared via emails unless encrypted in a secure manner or within secure computer walls.</p> <p>Your Health Information Rights</p> <p>Although your health record is the physical property of the healthcare practitioner or facility that completed it, the information belongs to you. Please check with your health care facility or pharmacy for any specific information regarding their privacy practices. Federal Law provides you the right to:</p> <ul style="list-style-type: none"> Request a restriction on certain uses and disclosures of your information. The health facility is not required to agree to a restriction, except in limited circumstances, such as for information gathered for judicial proceedings. Request a paper copy of a privacy notice from your health provider. Request a copy of this privacy notice related to 	<p>identifiable data collected for this current research project.</p> <ul style="list-style-type: none"> Inspect and obtain a copy of your health records. Amend your health record if you believe it is incorrect or incomplete. However, the health facility is not required to amend your health information and if your request is denied the health facility will provide you with information about your denial and how you can disagree with their denial. Authorize use of disclosure of any of your protected health information by using an Authorization to Use & Disclose Health Information Form. For example, you signed to allow your pharmacy to release information about your medication for this research project. Revoke your authorization to use or disclose health information except to the extent that action has already been taken. <p>Our Responsibilities.</p> <p>The researcher's agree to:</p> <ul style="list-style-type: none"> Respect all privacy requirements mentioned on the consent form you signed to participate, as approved by the University of Georgia's Institutional Review Board, the Office of Human Subjects Research. Maintain the privacy of your health information as required by law. Provide you with a notice as to our legal duties and privacy practices with respect to information we collect and maintain about you. Abide by the terms of this notice. Notify you if we are unable to agree to a requested restriction. Accommodate reasonable requests you may have to communicate health information by alternative means or at alternative locations. 	<p>Use and/or Disclosures for research purposes Without Your Written Authorization</p> <p>No information will be shared in an identifiable manner. All shared information will not be linked to your name.</p> <p>The following areas describe the ways the researchers in this study may use your health information. For each area, an example will be given.</p> <p>We will use your health information for research purposes. For example: Information obtained by your pharmacist will be recorded in your record and used to make aggregate analyses over a sample of records like yours. This helps researchers to draw conclusions about medication usage and pharmaceutical records for a group of people.</p> <p>We may have access to your computer IP address if you access a study Web site provided by us. For example, this is an automatic and necessary function when you log on to the study Web site, as with all Web sites. When you access external Web sites, we cannot assure that other Web providers maintain the security of your information.</p> <p>We may use your computer IP address for regular research functions. For example, this information may be seen by research collaborators or programmers during their regular activities to retrieve data from Web site utilization. There will be no direct link to your name and contact information provided to them. They will be required to assure the same strict confidentiality as mentioned in the consent form and this notice.</p> <p>This Privacy Policy applies as is to this research project only. Other research projects implemented by the College of Pharmacy reserve the right to change the Privacy Policy for their specific needs.</p> <p>We will not use or disclose your health information without your written authorization, except as described in this notice.</p>
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Appendix I Notice of Privacy (external side of leaflet)

<p>There will be no other disclosure of your health information made without your authorization. Anonymized data may be shared with:</p>	<p>For More Information or to Report a Problem</p>	<p>If you believe your privacy rights have been violated, you can file a complaint in writing with the College of Pharmacy Privacy Officer.</p> <p>If you would like to act upon any of your health information rights, as provided herein, have any questions or would like additional information, please contact the College of Pharmacy Privacy Officer at 705-542-7400.</p>	<p>Date: December 20, 2003</p>	<div><div>NOTICE OF HEALTH INFORMATION PRIVACY PRACTICES FOR THE COLLEGE OF PHARMACY RESEARCH PROJECT</div><div>"eHealth Information in Pharmacy"</div><div>College of Pharmacy Investigations Melanie Provost, B. Sc., Ph.D. Candidate Matthew Rem III, Rph., Ph.D., Professor The University of Georgia Athens, GA 30602</div></div>
<p>Research Associates: We may disclose your health information to our research associates so that they can make statistical analyses or research observations. We may disclose your computer IP address to research associates so that they can perform Weblog retrieval of aggregate data of the use of a study Web site. To protect your health information and computer identifiers, however, we require the research associates to appropriately safeguard your information.</p>	<p>Research: We may perform a follow up research study in the future that would necessitate contacting you. Your participation would be voluntary and the project would be approved by an institutional review board to ensure the respect of your privacy.</p>	<p>Required by Law: We may disclose health information for law enforcement purposes, as required by law, or in response to a valid subpoena. Federal law makes provision for your health information to be released to an appropriate health oversight agency, public health authority or attorney, provided that a workforce member or business associate believes in good faith that we have engaged in unlawful conduct or have otherwise violated professional or clinical standards and are potentially endangering one or more patients, workers or the public.</p>		

Appendix J Baseline Questionnaire (Paper-based)

FIRST Survey

ID

You can complete this survey now and return it to the pharmacy technician or complete it at home and return it by regular mail. The postage is pre-paid.

INSTRUCTION: check the box beside the answer of your choice. For example,

Which one is a fruit?

- ☒ An apple
- ☐ A steak
- ☐ A cookie
- ☐ I don't know

For some questions, you can check more than one box to indicate your answers. The sentence "Select all that may apply " will be written. For example,

What equipment do you need to access the Internet? Select all that may apply

- ☒ A computer
- ☒ A modem or cable connection
- ☐ A camera
- ☐ I don't know

After you completed the survey, simply fold and staple or tape it with the return mail showing.

About your medication

1. Please list the medication(s) you received at the pharmacy today, and indicate how long you have been taking it.

List only the medications received for high cholesterol, or diabetes, or high blood pressure.

Drug name(s): How many months or years have you been taking the medication:

2. Are you about to start a newly prescribed medication?

- ☐ Yes ;
If yes, which one? _____
(go to question 3)
- ☐ No (go to question 4)

3. Have you taken this new medication in the past month?

- ☐ YES, I have taken the prescribed medication before
- ☐ YES, I have taken a sample from the doctor's office How many days have you been taking the pills? _____ days.
- ☐ NO, I never took it before
- ☐ I don't know

4. What illnesses do you have? (select all that may apply)

- ☐ Arthritis
- ☐ High cholesterol
- ☐ High blood pressure
- ☐ Diabetes
- ☐ Previous heart attack
- ☐ Other
- ☐ None

5. How do you pay for your prescription medication?

- ☐ I pay all costs with my own money since my insurance does not cover drugs
- ☐ I pay most of the cost but my insurance pays or reimburses part of the cost.
- ☐ My insurance pays or reimburses most or all of the cost
- ☐ I don't know

About your use of the Internet**6. Where do you access the Internet the most for personal search?**

- ☐ From home
- ☐ From work
- ☐ From home and work about equal
- ☐ From public access places (library or other)
- ☐ Other
- ☐ I don't have access to the Internet

7. Which kind of Internet connection do you have?

- ☐ Dial-up access (Telephone modem)
- ☐ High speed, Cable modem, network, LAN or DSL (Digital Subscriber Line)
- ☐ I don't know

8. How long have you been using the Internet?

- ☐ Less than 6 months
- ☐ More than 6 months but less than 2 years
- ☐ 2-4 years
- ☐ More than 4 years

9. How many hours per week do you use the Internet including emailing?

Number of hours: _____

10. Thinking about the past year, would you characterize yourself as someone who:

- ☐ Has never looked for health information on the Internet
- ☐ Has received Internet health information from a friend or family member but has not looked up health information yourself;
- ☐ Has looked up health information on the Internet
- ☐ I don't know

11. How often do you use the Internet to look for advice or information about health?

- ☐ About once a week or more
- ☐ About once a month
- ☐ Every few months
- ☐ Less often
- ☐ Never (go to question 14)
- ☐ I don't know

12. How much, if at all, has getting health information on the Internet improved the way you take care of your health?

- ☐ A lot
- ☐ Some
- ☐ Only a little
- ☐ Not at all
- ☐ I don't know

13. When was the LAST time you went online to look for advice or information about health or health care?

- ☐ Within the last week
- ☐ In the last month
- ☐ In the last 6 months
- ☐ Before that
- ☐ I don't know

Appendix J (Cont'd)

The following part has questions with a different format. Here is an example of how to answer:

How much do you agree or disagree to the following statement?

Example.	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

How much do you agree or disagree with the following statement?

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
14. I feel confident using a new health Web site I have never used before.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. I feel confident finding health resources on the Web if the Web site had a Frequently Asked Questions (FAQ) section.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. I feel confident that I could find health resources on the Web if I had someone to call or email if I got stuck.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. I feel confident finding health resources on the Web by myself.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. I feel confident finding health resources on the Web as long as I have plenty of time to search.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. I feel confident that I could find health resources on the Web using a general search engine (ex.: Google, AOL, Yahoo).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

About you

20. What is your gender?

- ☐ Male
☐ Female

21. In general, how do you rate your own health?

- ☐ Excellent
☐ Good
☐ Only fair
☐ Poor
☐ I don't know

22. How old are you? _____

23. How would you describe yourself?

- ☐ American Indian or Alaska Native
☐ Asian
☐ Black or African American
☐ Hispanic or Latino
☐ Native Hawaiian or Other Pacific Islander
☐ White
☐ Other
☐ I don't know

24. What is your highest level of education?

- ☐ High school or less
☐ Some college
☐ College graduate
☐ Post-graduate studies or professional degree
(e.g. Master, Ph.D., MD)

25. When you read about health information, what language do you prefer?

- ☐ English
☐ Asian or Pacific Island languages
☐ Español
☐ Français
☐ Other

26. What is your annual household income?

- ☐ Less than \$15,000
☐ \$15,000 to \$24,999
☐ \$25,000 to \$34,999
☐ \$35,000 to \$49,999
☐ \$50,000 to \$74,999
☐ \$75,000 to \$99,999
☐ \$100,000 or more
☐ I don't know / Refuse

Thanks a lot for your help!

Please fold the survey and staple or tape with the return mail showing.

Appendix K Pre-screening Questionnaire – Internet Access

THE UNIVERSITY OF GEORGIA

RESEARCH MATERIAL – DO NOT DISCARD

Pre-screening Questionnaire

Ask patients with a new prescription for diabetes, hypertension or high cholesterol.

1. *Do you usually have access to the Internet for personal use?*

☐ YES ("yes" includes home, work, or friend's and relative's house, or self-reporting access to public cafe or library in the past 3 months)

☐ NO (or do not want to answer)

2. *Do you plan to keep your access to the Internet in the next 2 months?*

☐ YES

☐ NO

If YES to both questions → 1) give the invitation letter for interesting research project,

2) tell the patient to let you know in a few minutes if they are interested,

3) if so, give an envelope with consent to sign and collect.

Keep this card for the records even if there is any NO. Do not write the patient's name.

The number on the back of this card will not match the participants' number.

For questions, please refer to the *Pharmacy Research Material* or call Melanie Provost at (706) 296-5668.

Appendix L Patient's Instruction Page – Control Group

THE UNIVERSITY OF GEORGIA, COLLEGE OF PHARMACY

PARTICIPANT RESEARCH MATERIAL

INSTRUCTIONS

Thanks again for your participation in this research project!

Please:

- **Complete the survey included in this envelope.** Return it by regular mail (pre-paid postage) or give it to your pharmacist.
- Complete the survey that will be sent to you in about 2 months.

I personally thank you, and wish you a good day!

Melanie Provost, B.Sc., Ph.D. student

Appendix M Patient's Instruction Page – Ehealth Group

INSTRUCTIONS

Thanks again for your participation in this research project!

Please:

1. **Complete the survey included in this envelope.** Return it by regular mail (pre-paid postage) or give it to your pharmacist.
2. **Make 4 visits to the study Web site** during the next 2 months.
 - Go to **www.RxLinx.org**
 - Enter the site using your username and the password.
 - RxLinx Web site suggests you Web sources of information about your medication and condition.
 - When you're done, please don't forget to click the LOGOFF button.
3. Complete the survey that will be sent to you in about 2 months.

User name

Use your last name and year of birth to create your login name.

For example, Nancy Smith born in 1962 will have the login: **smith62**

Detach the reminder card from this page, and keep it in your wallet or a place to remember.

How many times should I visit the Web site?

You need to visit it 4 times. A good way can be to do it once per week!

You can visit the Web site as much as you need.

Can I go directly to other web sites instead of using RxLinx study site?

For our study, participants need to reach the Web sources of information through the study Web site called RxLinx. RxLinx will take you to web sites for use in this study.

Please try to always use RxLinx.org during the study period when you need to reach information about your medication and disease.

I personally thank you, and wish you a good day!

Melanie Provost, B.Sc., Ph.D. student

Appendix N Final Questionnaire (Online and paper-based versions) – Dyslipidemia

FINAL Survey

ID

After you completed the survey, simply fold and staple or tape it with the return mail showing. The postage is pre-paid.

INSTRUCTION: check the box beside the answer of your choice. For some questions, you can check more than one answer to pick. The sentence "Select all that may apply" will be written. Here is an example of question:

Ex.: What equipment do you need to access the Internet? Select all that may apply

- ☒ A computer
☒ A modem or cable connection
☐ A camera
☐ I don't know

PART 1

About your medication

1. About two months ago, you agreed to participate in this research project because you are taking a prescribed medication for treatment of high cholesterol. Please write the name(s) of the medication(s):

2. Have you been taking this prescription drug since enrolling in this study?

- ☐ Yes (go to question 4)
☐ No
☐ I don't know

3. If not, what was the reason for stopping?

- ☐ My doctor changed the treatment for some other drug
☐ I decided that I did not need the medication anymore
☐ I decided to stop it because it gave me side effects
☐ I decided to stop it because I felt better
☐ I read something on the Web that convinced me to stop the treatment
☐ I could not afford it
☐ Other reason

4. Since you started your treatment, which sources of information about your medication have you used? (select all that may apply)

- ☐ Pharmacy print out
☐ Pharmacist talked with me
☐ TV ads about my medication
☐ Newspaper or magazine articles
☐ Friends or family members who knew about the medication
☐ Internet
☐ Other
☐ I did not use or need any sources

5. Since you started your treatment, which sources of information about your disease have you used? (select all that may apply)

- ☐ Pharmacy print out
☐ Pharmacist talked with me
☐ TV ads about my disease
☐ Newspaper or magazine articles
☐ Friends or family members who knew about the disease
☐ Internet
☐ Other
☐ I did not use or need any sources

6. How satisfied are you with the information provided to you at the pharmacy about your medication?

- ☐ Very dissatisfied
☐ Somewhat dissatisfied
☐ Neither satisfied nor dissatisfied
☐ Somewhat satisfied
☐ Very satisfied

7. How satisfied are you with information provided to you at the pharmacy about your disease?

- ☐ Very dissatisfied
☐ Somewhat dissatisfied
☐ Neither satisfied nor dissatisfied
☐ Somewhat satisfied
☐ Very satisfied

For some of the following questions you will be asked to refer to the time period since the beginning of the project, say from when you signed the consent form until now. It has been about 2 months.

The following part has questions with a different format. Here is an example on how to answer:

Example: How much do you agree or disagree with the following statement?

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
Most people use a computer to access the Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>

8. Thinking about the time since you begun this project, how much do you agree or disagree with the following statements?

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I know much more about my medication(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have learned a lot about the potential side effects related to my medication(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have learned a lot about my disease(s)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have learned a lot about how to eat healthier food	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have not learned much about how to become more active	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I understand more about the risk of having heart problems.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

PART 2**About your experience with your medication**

9. Tell us more about your experience with your medication for high cholesterol.

	None of the time	Some of the time	Neutral	Most of the time	All of the time
How often do you forget to take your cholesterol medicine?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you decide not to take your cholesterol medicine?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you forget to have your prescription refilled?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you run out of pills?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you skip your cholesterol medicine before you go to the doctor?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you miss taking your medicine when you feel sick?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you take someone else's cholesterol pills?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How often do you miss taking your cholesterol pills when you are careless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

10. How much do you agree or disagree with the following statements?

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I am tempted to miss a dose when I think there may be long-term side effects.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I sometimes skip doses when I feel better.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am tempted to miss doses when I feel depressed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I miss doses when I get out of my daily routine.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I miss doses when I go out of town.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I sometimes skip doses when I am short on money	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I believe that I will be still taking my cholesterol medication 2 years from now.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

PART 3**About your relationship with your health professionals**

11. How many questions did you ask the pharmacist last time you refilled your prescriptions for high cholesterol, high blood pressure, and/or diabetes?

- ☐ None
- ☐ Just one
- ☐ More than one
- ☐ I did not talk to the pharmacist
- ☐ I don't know

12. Since you enrolled in this study, about how many pages did you print out from the Internet and keep to show to your pharmacist or doctor?

- ☐ None, I didn't use the Internet
- ☐ None, although I used the Internet
- ☐ 1-5 pages
- ☐ 6 pages or more
- ☐ I don't know

13. When you got your prescription filled, how much of the patient information leaflet did you read?

- ☐ I read all of the leaflet
- ☐ I only glanced the leaflet
- ☐ I did not read the leaflet
- ☐ I did not receive a leaflet

PART 5**Knowledge about the disease and its treatment**

14. How long is the drug treatment for high cholesterol for the majority of people?

- ☐ Until normal levels of cholesterol are obtained
- ☐ For 1-2 years
- ☐ Forever
- ☐ I don't know

15. If you experience side effects of your drugs, does this mean you should stop taking them?

- ☐ Yes
- ☐ No
- ☐ I don't know

16. What organ in the body makes cholesterol?

- ☐ Pancreas
- ☐ Liver
- ☐ Kidney
- ☐ I don't know

17. Which type of cholesterol is "good", has a protective effect and should be elevated?

- ☐ Triglycerides
- ☐ LDL
- ☐ HDL
- ☐ None, there is no good cholesterol
- ☐ I don't know

18. Having total cholesterol levels less than 200 mg/dl help you live longer and having less risk of heart problems.

- ☐ True
- ☐ False
- ☐ I don't know

19. What is a heart attack?

- ☐ When a clot blocks the blood going to the brain that stop the heart
- ☐ An infection of the heart
- ☐ A blockage of the blood vessels of the heart
- ☐ A change in heart rhythm
- ☐ I don't know

20. People taking their medication properly for high cholesterol do not need to follow a specific diet.

- ☐ True
- ☐ False
- ☐ I don't know

21. Daily moderate-intensity activities, like walking for pleasure, do not help to reduce the risk for heart problems.

- ☐ True
☐ False
☐ I don't know

22. Having high cholesterol levels is considered an important risk factor for coronary heart disease (CHD) similar to smoking and high blood pressure.

- ☐ True
☐ False
☐ I don't know

23. What is a stroke?

- ☐ A variation in the heart rhythm
☐ An infection of the muscle of the heart
☐ A rupture or blockage of an artery to the brain
☐ A blockage of the blood vessels of the heart
☐ I don't know

PART 5

About your Internet Experience

24. How many hours per week do you use the Internet for emailing? Write your answer.

Number of hour(s): _____

25. How many hours per week do you use the Internet other than emailing? Write your answer.

Number of hour(s): _____

26. How likely or unlikely is it for you to use the Web to...

	Very unlikely	Unlikely	Neutral	Likely	Very likely
Find current information like health news, new drug discoveries, clinical trials, and epidemic outbreaks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get information about medications, devices and health services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get immediate knowledge of big health news events	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Get health and drug information you can trust	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Find health information that is new to you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Learn about controversial health information	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Learn about healthy lifestyles (including nutrition, exercise, prevention)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

27. How much do you agree or disagree with the following statements?

Using the Web to find health information...

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
...I feel I have more power to make decisions about my health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...can help me talk with my doctor about my health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...I feel that getting the information is overwhelming.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...makes me confused as to the right course of treatment for my disease.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...makes me aware of conflicting medical information about my disease and its treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
...helps me take better care of my own health.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

28. Since you enrolled in this study, which Web sources of health information did you use? (select all that may apply)

- ☐ None
- ☐ The RxLinx Web site
- ☐ Health specific Web site (for example, WebMD, MayoClinic)
- ☐ Other Web sites (for example, CNN/health, MSN health news, health.Yahoo)
- ☐ Search engine searches (Google, Yahoo, AOL, or other)

29. How frequently, if at all, did you visit the Web site provided by the company making the prescribed medication you are taking for treating your high cholesterol?

- ☐ Very often
- ☐ Often
- ☐ Occasionally
- ☐ Rarely (at least once)
- ☐ Never

30. How frequently did you seek information using the Internet about your medication or disease since you enrolled in this study?

- ☐ Very often
- ☐ Often
- ☐ Occasionally
- ☐ Rarely (at least once)
- ☐ Never → If you answered "Never", skip the remaining questions, and mail your booklet.

31. How trustful, if at all, was the health information you found on the Internet?

- ☐ Very trustful
- ☐ Somewhat trustful
- ☐ Not too trustful
- ☐ Not at all trustful
- ☐ I do not know

32. How much, if at all, has getting health information on the Internet improved the way you take care of your health?

- ☐ A lot
- ☐ Some
- ☐ Only a little
- ☐ Not at all
- ☐ I don't know

33. How satisfied are you with the information you found online about your prescribed medication?

- ☐ Very dissatisfied
- ☐ Somewhat dissatisfied
- ☐ Neither satisfied nor dissatisfied
- ☐ Somewhat satisfied
- ☐ Very satisfied

34. How much did the information you found online about your medication cause you to worry about taking your medication?

- ☐ Not at all worried
- ☐ A little worried
- ☐ Worried
- ☐ Worried a lot

35. Since you enrolled in this study, is there one thing that stands out in your mind that you learned on the Web about your health or medications? Write your answer.

PART 6

About your experience using the study Web site RxLinx.org

36. If you are provided access, how likely or not are you to continue using the Web site RxLinx.org ?

- ☐ Very unlikely
- ☐ Somewhat unlikely
- ☐ Neither likely or unlikely
- ☐ Somewhat likely
- ☐ Very likely

37. How difficult or easy was it to use the study Web site (RxLinx)?

- ☐ Very easy
- ☐ Somewhat easy
- ☐ Neither easy or difficult
- ☐ Somewhat difficult
- ☐ Very easy

**Thanks a lot for your help!
Please fold the survey and staple or tape
with the return mail showing.**

Appendix O Knowledge Questionnaire – Hypertension group

1. How long is the drug treatment for high blood pressure for the majority of people?

- ☐ Until normal levels of blood pressure are obtained
- ☐ For 1-2 years
- ☐ Forever
- ☐ I don't know

2. If you experience side effects of your drugs, does this mean you should stop taking them?

- ☐ Yes
- ☐ No
- ☐ I don't know

3. What organ in the body most involved in blood pressure apart from the brain and the heart?

- ☐ Thyroid
- ☐ Kidney
- ☐ Adrenal gland
- ☐ I don't know

4. Which are the higher limits of normal blood pressure values in the adult population?

- ☐ Less than 160/105 mm Hg
- ☐ Less than 150/90 mm Hg
- ☐ Less than 140/90 mm Hg
- ☐ I don't know

5. Having the blood pressure reduce to an optimal goal help you live longer and having less risk of heart problems.

- ☐ True
- ☐ False
- ☐ I don't know

6. What is a heart attack?

- ☐ When a clot blocks the blood going to the brain that stop the heart
- ☐ An infection of the heart
- ☐ A blockage of the blood vessels of the heart
- ☐ A change in heart rhythm
- ☐ I don't know

7. People taking their medication properly for high blood pressure do not need to follow a specific diet.

- ☐ True
- ☐ False
- ☐ I don't know

8. What is a stroke?

- ☐ A variation in the heart rhythm
- ☐ An infection of the muscle of the heart
- ☐ A rupture or blockage of an artery to the brain
- ☐ A blockage of the blood vessels of the heart
- ☐ I don't know

9. Daily moderate-intensity activities, like walking for pleasure, do not help to reduce the risk for heart problems.

- ☐ True
- ☐ False
- ☐ I don't know

10. Having high blood pressure is also considered an important risk factor for coronary heart disease (CHD) similar to smoking.

- ☐ True
- ☐ False
- ☐ I don't know

Appendix P Knowledge Questionnaire – Diabetes group

1. How long is the drug treatment for diabetes for the majority of people?

- ☐ Until normal levels of blood sugar levels are obtained
- ☐ For 1-2 years
- ☐ Forever
- ☐ I don't know

2. If you experience side effects of your drugs, does this mean you should stop taking them?

- ☐ Yes
- ☐ No
- ☐ I don't know

3. What organ in the body should make insulin?

- ☐ Liver
- ☐ Pancreas
- ☐ Kidney
- ☐ I don't know

4. Which are the limits of blood glucose values for diabetes before a meal?

- ☐ Lower limit: > 100 mg/dl,
Upper limit: < 160 mg/dl
- ☐ Lower limit: > 80 mg/dl,
Upper limit: < 120 mg/dl
- ☐ Lower limit: > 80 mg/dl,
Upper limit: < 160 mg/dl
- ☐ I don't know

5. Having the sugar levels controlled to an optimal goal reduce your risk of becoming blind or having an amputation..

- ☐ True
- ☐ False
- ☐ I don't know

6. What is a heart attack?

- ☐ When a clot blocks the blood going to the brain that stop the heart
- ☐ An infection of the heart
- ☐ A blockage of the blood vessels of the heart
- ☐ A change in heart rhythm
- ☐ I don't know

7. People taking their medication properly for diabetes do not need to follow a specific diet.

- ☐ True
- ☐ False
- ☐ I don't know

8. What is a stroke?

- ☐ A variation in the heart rhythm
- ☐ An infection of the muscle of the heart
- ☐ A rupture or blockage of an artery to the brain
- ☐ A blockage of the blood vessels of the heart
- ☐ I don't know

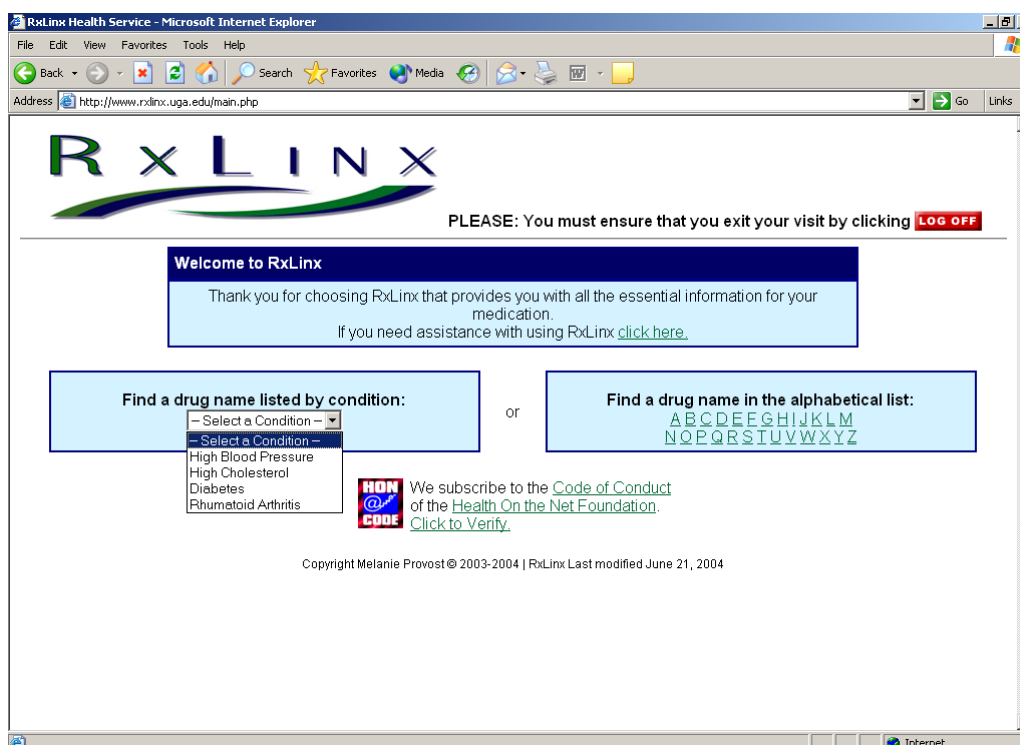
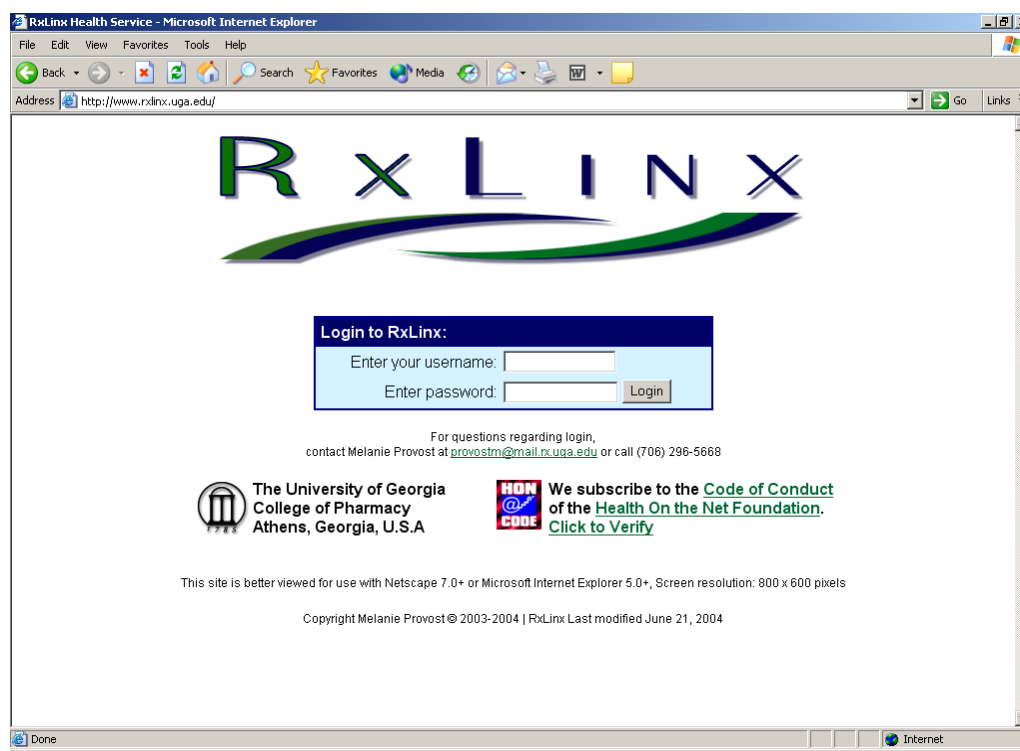
9. Daily moderate-intensity activities, like walking for pleasure, do not help to reduce the risk for heart problems.

- ☐ True
- ☐ False
- ☐ I don't know

10. Having diabetes is considered an important risk factor for coronary heart disease (CHD) similar to smoking and high blood pressure.

- ☐ True
- ☐ False
- ☐ I don't know

Appendix Q Study Web site's Sample of Pages – RxLinX.org



RxLinX Health Service - Microsoft Internet Explorer

File Edit View Favorites Tools Help

Back Forward Stop Search Favorites Media Print Mail RSS

Address <http://www.rxlinx.uga.edu/list.php#a> Go Links

R x L I N X

PLEASE: You must ensure that you exit your visit by clicking **LOG OFF**

Quick Links

[Home](#)

[List all Drugs & Conditions](#)

Drug listed by condition:

When You Are Done

PLEASE, it is important to exit at the end of your visit, click **LOG OFF**

RxLinX Information

[About Us](#)

[Privacy Policy](#)

[Terms of Use](#)

[Accreditation](#)

[Contact Us](#)

High Blood Pressure, High Cholesterol, or Diabetes
General Information about [High Blood Pressure](#), [High Cholesterol](#), [Diabetes](#), [Rheumatoid Arthritis](#)

List of Medications
Find the name of your medication in the following list

Click a letter to jump to the drug:
[A](#)[B](#)[C](#)[D](#)[E](#)[F](#)[G](#)[H](#)[I](#)[J](#)[K](#)[L](#)[M](#)[N](#)[O](#)[P](#)[Q](#)[R](#)[S](#)[T](#)[U](#)[V](#)[W](#)[X](#)[Y](#)[Z](#)

A

[ACARBOSE](#)

[ACCUPRIL ® \(QUINAPRIL HYDROCHLORIDE\)](#)

[ACEBUTOLOL HYDROCHLORIDE](#)

[ACEON ® \(PERINDOPRIL ERBUMINE\)](#)

[ACTOS ® \(PIOGLITAZONE\)](#)

[ADALAT CC ® \(NIFEDIPINE\)](#)

[ADVICOR ® \(NIACIN; LOVASTATIN\)](#)

[ALDACTAZIDE ® \(HYDROCHLOROTHIAZIDE; SPIRONOLACTONE\)](#)

[ALDACTONE ® \(SPIRONOLACTONE\)](#)

[ALDOCLOR-150 ® \(CHLOROTHIAZIDE; METHYLDOPA\)](#)

[ALDOMET ® \(METHYLDOPA\)](#)

[ALDORIL 15 ® \(HYDROCHLOROTHIAZIDE; METHYLDOPA\)](#)

[ALTACE ® \(RAMIPRIL\)](#)

[AMARYL ® \(GLIMEPIRIDE\)](#)

[AMILORIDE](#)

[AMILORIDE HYDROCHLORIDE; HYDROCHLOROTHIAZIDE](#)

[AMLODIPINE BESYLATE](#)

[AMLODIPINE BESYLATE; BENAZEPRIL HYDROCHLORIDE](#)

[ANAKINRA](#)

[APRESOLINE ® \(HYDRALAZINE HYDROCHLORIDE\)](#)

[AQUATENSEN ® \(METHYCLOTHIAZIDE\)](#)

[ARALEN ® \(CHLOROQUINE\)](#)

[ARAVA ® \(LEFLUNOMIDE\)](#)

[ASPIRIN](#)

[ATACAND ® \(CANDESARTAN CILEXETIL\)](#)

[ATACAND-HCT ® \(ACARBOSE\)](#)

[ATENOLOL](#)

[ATENOLOL; CHLORTHALIDONE](#)

[ATORVASTATIN](#)

[ATROMID-S ® \(CLOFIBRATE\)](#)

[AVALIDE ® \(HYDROCHLOROTHIAZIDE; IRBESARTAN\)](#)

[AVANDAMET ® \(METFORMIN; ROSIGLITAZONE\)](#)

[AVANDIA ® \(ROSIGLITAZONE MALEATE\)](#)

[AVAPRO ® \(IRBESARTAN\)](#)

[AZATHIOPRINE](#)

[AZULFIDINE ® \(SULFASALAZINE\)](#)

B

[BAYCOL ® \(CERIVASTATIN\)](#)

[BENAZEPRIL HYDROCHLORIDE](#)

[BENAZEPRIL HYDROCHLORIDE; HYDROCHLOROTHIAZIDE](#)

[BENDROFLUMETHIAZIDE](#)

[BENDROFLUMETHIAZIDE; NADOLOL](#)

[BENICAR ® \(OLMESARTAN\)](#)

[BENICAR-HCT ® \(HYDROCHLOROTHIAZIDE; OLMESARTAN\)](#)

[BETAXOLOL HYDROCHLORIDE](#)

[BEXTRA ® \(VALDECOXIB\)](#)



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of the
Health On the Net Foundation.

[Click to Verify.](#)

Note: Brand names mentioned are the properties of the respective companies.



Note: All links of general sources of information were randomly reordered when the user refreshed a page. Brand names mentioned are the properties of the respective companies.

RxLinX Health Service - Microsoft Internet Explorer

Address: <http://www.rxlinx.uga.edu/result.php>

R x L I N X Results for mayoclinic - <http://www.mayoclinic.com/invokc.cfm?objectid=3E31F938-7546-4783-B678BD0AE5D79925>
Instructions: You are visiting an external site. Navigate this site as long as you need.
 When you are done, click the upper-right corner X, or [click here](#) to close the window. You will return to the list of sources.

MayoClinic.com
 Reliable information for a healthier life

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Drugs & Supplements July 9, 2004

[Format to print](#)

IN THIS ARTICLE

- [US Brand Names](#)
- [Canadian Brand Names](#)
- [Description](#)
- [Before Using This Medicine](#)
- [Proper Use of This Medicine](#)
- [Precautions While Using This Medicine](#)
- [Additional Information](#)
- [Notes](#)

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Drug Information provided by: [Micromedex](#)

Angiotensin-converting Enzyme (ACE) Inhibitors (Systemic)

US Brand Names [Back to top](#)

- Accupril [10](#)
- Aceon [9](#)
- Altace [11](#)
- Capoten [2](#)
- Lotensin [1](#)
- Mavik [12](#)
- Monopril [8](#)
- Prinivil [7](#)
- Univas [8](#)
- Vasotec
- Zestril [7](#)

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- Accupril [10](#)
- Altace [11](#)
- Capoten [2](#)

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Address: <http://www.rxlinx.uga.edu/result.php>

R x L I N X Results for companyurl - http://www.altace.com/index_flash.asp
Instructions: You are visiting an external site. Navigate this site as long as you need.
 When you are done, click the upper-right corner X, or [click here](#) to close the window. You will return to the list of sources.

GLOSSARY | PRODUCT INFORMATION | SITE MAP | CONTACT US

ALTACE
 ramipril capsules

Understanding Your Cardiovascular Risks

What Is ALTACE?

Why Doctors Prescribe ALTACE

Risk Reduction for People Aged 55+

Clinical Studies

Talking to Your Doctor

Support for People Taking ALTACE

Important Safety Information

Do not take ALTACE during pregnancy, as death or injury to your unborn child may result.
[Read more below.](#) →

Q: Why ALTACE?
A: ALTACE may help you **reduce the risk** of heart attack, stroke, or cardiovascular death if you're a person aged **55+**

- And have had a previous [heart attack](#)
- And/or have had a previous [stroke](#)
- And/or have [diabetes](#) plus an additional cardiovascular risk factor, such as high blood pressure or high cholesterol, or you are a smoker
- And/or have a history of [coronary artery disease](#), such as angina, previous bypass surgery, or angioplasty (stenting or ballooning)
- And/or have peripheral vascular disease

ALTACE is also a standard therapy for [controlling high blood pressure](#) in adults.

Is ALTACE right for you?

[Take a quick self-assessment](#) to see whether ALTACE might be right for you. Then talk to your doctor about ALTACE. →

Source: <http://www.altace.com> © 2004, Monarch Pharmaceuticals, Inc., a wholly owned subsidiary of King Pharmaceuticals™, Inc.
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Sample of Internal Administrative tracking reports

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Totals for Entire Study

	Total	Webmd	Medlineplus	Rxlist	Healthsquare	Medicinenet	Healthatoz	Drugdigest	Drugs.com	Mayoclinic
Unique Visitors	54	30	17	24	14	15	24	22	19	31
Links Tracked	388	62	31	46	22	25	32	47	28	62
Sessions	193	50	27	38	20	22	30	40	25	53

Summary of Sessions

Participant	Times Visited	Session Start	Session End	Elapsed Time	
User1	9	Apr 4 @ 7:45pm	Apr 4 @ 8:00pm	14 min 45 sec	details of this study details of this user
User2	6	Apr 10 @ 11:06pm	Apr 10 @ 11:52pm	46 min 41 sec	details of this study details of this user


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User1

r 4 @ 7:45pm - 8:00pm for 14 min 45 sec

Name	Source	Position	Time Viewed	Time Before Next Link
HYZAAR (HYDROCHLOROTHIAZIDE; LOSARTAN POTASSIUM)	mayoclinic	3	7:47:36 pm	5 min 51 sec
HYZAAR (HYDROCHLOROTHIAZIDE; LOSARTAN POTASSIUM)	rxlist	7	7:53:27 pm	2 min 30 sec
HYZAAR (HYDROCHLOROTHIAZIDE; LOSARTAN POTASSIUM)	webmd	5	7:55:57 pm	1 min 51 sec
HYZAAR (HYDROCHLOROTHIAZIDE; LOSARTAN POTASSIUM)	drugscom	4	7:57:48 pm	2 min 54 sec

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Address <http://www.rxlink.uga.edu/adm/details.php?pid=9> Go Links » Accredited

User1 Apr 11 @ 2:24pm - Incomplete for N/A

Name	Source	Position	Time Viewed	Time Before Next Link
HYDROCHLOROTHIAZIDE; LOSARTAN POTASSIUM	medlineplus	3	2:26:35 pm	5 min 50 sec
LIPITOR (ATORVASTATIN)	rxlist	6	2:32:25 pm	1 min 21 sec
LIPITOR (ATORVASTATIN)	rxlist	1	2:33:46 pm	N/A

User1 Apr 11 @ 5:01pm - 5:12pm for 11 min 6 sec

Name	Source	Position	Time Viewed	Time Before Next Link
LIPITOR (ATORVASTATIN)	webmd	4	5:02:07 pm	10 min 4 sec

User1 Apr 22 @ 10:11pm - 10:17pm for 5 min 57 sec

Name	Source	Position	Time Viewed	Time Before Next Link
HYZAAR (HYDROCHLOROTHIAZIDE; LOSARTAN POTASSIUM)	healthsquare	4	10:11:41 pm	5 min 20 sec

User1 Apr 25 @ 8:29am - 8:43am for 13 min 9 sec

Name	Source	Position	Time Viewed	Time Before Next Link
FENOFIBRATE	drugdigest	7	8:30:46 am	3 min 1 sec
High Blood Pressure	medlineplus	4	8:33:47 am	9 min 16 sec

User1 May 2 @ 12:13am - 12:27am for 13 min 38 sec

Name	Source	Position	Time Viewed	Time Before Next Link
HYZAAR (HYDROCHLOROTHIAZIDE; LOSARTAN POTASSIUM)	medicinenet	2	12:14:09 am	6 min 28 sec
HYZAAR (HYDROCHLOROTHIAZIDE; LOSARTAN POTASSIUM)	healthsquare	5	12:20:37 am	6 min 45 sec

User1 May 11 @ 9:20pm - 9:27pm for 7 min 17 sec

Name	Source	Position	Time Viewed	Time Before Next Link
HYZAAR (HYDROCHLOROTHIAZIDE; LOSARTAN POTASSIUM)	drugdigest	3	9:21:47 pm	3 min 55 sec
FENOFIBRATE	companyurl	N/A	9:25:42 pm	2 min 12 sec

User1 Jun 15 @ 8:58am - Incomplete for N/A

Name	Source	Position	Time Viewed	Time Before Next Link
No information tracked				

User1 Jun 15 @ 9:16am - 9:17am for 0 min 19 sec

Name	Source	Position	Time Viewed	Time Before Next Link
No information tracked				

Done Internet

