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Editorial

Internet use in disease management for home care patients: A call for papers

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Disease Management and the Internet

Disease Management refers to "a set of coordinated healthcare interventions and communications for populations with conditions in which patient self-care efforts are significant." [1] Disease management supports the care plan and enhances the provider-patient relationship. It emphasizes prevention of deterioration and/or complications using evidence-based practice guidelines. It aims to improve the patient's overall health by continuously assessing clinical and economic outcomes. The goals of disease management are to manage medical conditions over time, improve outcomes, lower costs, and support patient-provider interaction, patient education and monitoring.

Patients with chronic illnesses account for a great portion of healthcare costs. An efficient disease management system should dramatically reduce medical and administrative costs, while enriching the physician-patient communication and improving health outcomes.

Earlier efforts in utilizing information technology demonstrated the barriers of attempting to integrate systems without a common protocol and developing systems with a long implementation cycle and at increased overall costs. However, the diffusion of the Internet has the potential to empower patients and address these barriers by providing the means for technically flexible applications with shorter implementation cycles.

Internet technologies are being utilized for disease management in many clinical areas in the last few years. In [Textbox 1](#) some examples of web-based disease management applications are provided, grouped by clinical area. Internet technologies allow to connect patients with providers, link home-care with hospital and ambulatory care, facilitate information exchange, communication, and collaboration between and among patients, caregivers, and health care providers. Patient self-management education is a central component of disease management, and the Internet supports this by enabling the transmission of tailored health information or automated reminders to patients or their caregivers. Web-based electronic health records are another avenue of enhancing communication among stakeholders to

coordinate care, and patient accessible records empower patients to improve self-care in the age of consumer health informatics [2]. The convergence of the Internet with everyday household items such as TV sets, refrigerators, Personal Digital Assistants (PDAs) and mobile phones [3] opens up new channels of communicating with patients through information technology and empowering them to manage their disease.

Challenges for web-based disease management systems

Factors that will be critical for the diffusion of Internet based disease management systems include design; privacy and confidentiality; patient and provider acceptance; costs and reimbursement structures; and access to and ownership of data.

Usability

A great number of home care patients who require disease management are elderly and/or have functional limitations. A functional limitation describes a "reduced sensory, cognitive or motor capability associated with human aging, temporary injury, or permanent disability that prevents a person from communicating, working, playing or simply functioning in an environment where other people in the population can function." [11]. Although the Internet seems to have the potential to revolutionize the process of health care delivery and empower patients to become more active in the care process, the fastest growing segment of the US population — i.e., people over the age of 50 years — are at a disadvantage because designers of both software and hardware technology fail to consider them as a potential user group. Usability and accessibility issues are important quality criteria for web-based interventions, but are frequently ignored by designers and evaluators [12]. The design of a usable web-based information system for healthy users who are familiar with computer technology is a challenge. When a system needs to address age-related constraints and the functional limitations of inexperienced users, it becomes even more difficult. Designers of a system for home care patients should aim to increase its functional accessibility [13] and employ rigorous usability testing methods.

Textbox 1. Examples of web-based disease management applications**Asthma management**

Disease management for asthma patients has the potential of early detection of critical situations and timely intervention.

One example of Internet utilization for asthma management is the home asthma telemonitoring (HAT) [4] system which provides patients with continuous individualized help in the daily routine of asthma self-care and notifies health care providers if certain clinical conditions occur.

Diabetes management

Diabetes has in many cases an asymptomatic nature. The time frame between sustained hyperglycemia and observable complications can be extended, thus making a long-term program of secondary prevention an essential part of appropriate diabetes care. The Center for Health Services Research, Henry Ford Health System in Detroit, Michigan, developed a Web-based Diabetes Care Management Support System (DCMSS) to support the provision of routine care to patients with diabetes [5]. The system was evaluated within a nonrandomized, longitudinal study and findings suggest that web-based systems of clinical practice guidelines, patient registries, and performance feedback have the potential to improve the rate of routine testing among patients with diabetes. McKay and colleagues studied the development and feasibility of a Web site for diabetes self-management that emphasized personalized goal setting, feedback, and social support [6]. The Telematic Management of Insulin-Dependent Diabetes Mellitus (T-IDDM) project, funded by the European Union, piloted, implemented and evaluated a distributed computer-based system for the management of insulin-dependent diabetes mellitus. The goal of this system is to utilize Internet technology to support the normal activities of the physicians and patients involved in the care of diabetes by providing them with a set of automated services ranging from data collection and transmission to data analysis and decision support [7]. The system includes a module allowing patients to automatically download their monitoring data from the blood glucose monitoring device, and to send them to the hospital data-base. The system provides physicians with a set of tools for data visualization, data analysis and decision support, and allows them to send messages, including therapeutic advice, to the patients [8].

Post-Transplant care

Regular spirometry monitoring of lung transplant recipients is essential to early detection of acute infection and rejection of the allograft. A prospective study investigated the impact of a user-friendly, Internet-based telemonitoring system providing direct transmission of home spirometry to the hospital. The authors concluded that home monitoring of pulmonary function in lung transplant recipients via the Internet is feasible and provides very reproducible data; yet "it has only a mild sensitivity for the detection of acute allograft dysfunction." [9].

Wound care

The TeleHomeCare Project at the University of Minnesota utilized low-cost commercially available monitoring devices and Internet access to enable congestive heart failure, chronic obstructive pulmonary disease and wound care patients at home to interact with health care providers at the agency. Individualized web pages were designed for each patient including a diary system with questionnaires to be filled out daily. The questionnaire included questions about vital signs (such as weight, blood pressure or temperature), symptoms, and overall well-being and nutrition. Alerts were triggered when a patient's response required immediate medical attention according to predefined rules [10].

Privacy and Confidentiality

The healthcare sector worldwide is facing a great number of challenges and regulations in regard to the confidentiality, availability and integrity of individual health information. In the United States, the Notice of the Proposed Rule from the Department of Health and Human Services concerning Security and Electronic Signature Standards was introduced in 1998 [14]. The Proposed Rule falls under the umbrella of the Health Insurance Portability and Accountability Act (HIPAA) that was passed in 1996. This Proposed Rule became law in 2000 in the United States and suggests standards for the security of individual health information and electronic signature use for health care providers, systems and agencies. These will use the Security Standards to develop and maintain the security of all electronic health information. Similar frameworks exist in the European Union and Canada [15].

Patient and provider acceptance

The diffusion of an innovation depends to a great extent to the attitudes of the population to which it is being introduced to. This of course applies to web-based disease management applications as well where users (patients, caregivers, family members, providers) have to accept the use of technology and be willing to receive training and integrate the application into the care delivery process.

Costs and reimbursement

While there is some evidence demonstrating the cost-effectiveness of traditional disease management (e.g., a retrospective analysis of 7,000 patients found a \$50 per member, per month savings in diabetes treatment costs over twelve months and eighteen percent decrease of admissions [16]) there is little evidence as of yet of the cost-effectiveness or even possible long term cost reduction through utilization of Internet in disease management. Cost analysis and/or cost-effectiveness studies will contribute to discussions about possible reimbursement issues of web-based monitoring services and the question of which party will bear the costs of implementing and maintaining such a web-based system.

Access to and ownership of the data

In many web-based applications in home care, patients enter or record monitoring data and transmit them daily to a web server owned and maintained by a private third party that allows providers to log in and access the data of their patients. The question of patients' rights to access parts or all of their record, the physical storage and access rights and the issue of data ownership become even more essential when monitoring data are stored physically at a separate location controlled by a private company. The implications are not only possible threats to data privacy but extend to ethical and political debates about restructuring the care delivery process and introducing new key players.

Call for papers

The *Journal of Medical Internet Research* is pleased to announce a theme issue on Internet utilization for disease management in home care. We invite researchers in this field to submit papers that focus on this area such as:

- Studies (preferably randomized controlled trials) that demonstrate the impact of Internet utilization in disease management on
 - health outcomes
 - patient self-management education
 - cost of care
- Papers that describe the development and evaluation of web-based disease management applications
- Studies that address design issues for such applications
- Studies that describe innovative web-based patient monitoring systems and/or devices (an evaluation component is strongly encouraged)
- Studies that propose a sustainable and cost-effective model for web-based disease management
- Manuscripts that address the issues of privacy and confidentiality of patient data (e.g. the impact of final HIPAA privacy rule on disease management via Internet for the US)

- Critical comments and opinion papers
- Systematic reviews synthesizing our current state of knowledge in this field

All papers will undergo a normal peer-review process. Papers received before June 1st, 2003 will have the best chances for publication. The theme issue is planned to appear in late 2003. We will be actively looking for a sponsor of this theme issue, which will enable us to waive our usual article processing fee for papers published in this theme issue. The theme issue will be Medline-indexed and be made freely accessible on the web and possibly in a printed version.

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Conflicts of Interest

None declared.

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Original Paper

Users of Internet Health Information: Differences by Health Status

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Abstract

Background: Millions of consumers have accessed health information online. However, little is known about their health status.**Objective:** To explore use of Internet health information among those who were sicker (fair/poor general health status) compared with those reported being healthier.**Methods:** A national, random-digit telephone survey by the Pew Internet & American Life Project identified 521 Internet users who go online for health care information. Our primary independent variable was general health status rated as excellent, good, fair, or poor. Patterns of Internet use, and types of information searched were assessed.**Results:** Among the 521 users, 64% were female, most (87%) were white, and median age was 42 years. Most individuals indicated that they learned something new online (81%) and indicated that they believe most information on the Internet (52%). Compared with those with excellent/good health, those with fair/poor health (N = 59) were relative newcomers to the Internet but tended to use the Internet more frequently, were more likely to use online chats, were less likely to search for someone other than themselves, and were more likely to talk about the new information with their physician (odds ratio 3.3 [95% confidence interval 1.8-6.3]), after adjustment for age, education and income.**Conclusions:** Health care professionals should be aware that their sicker patients are more likely to ask them about information they found online. Physicians, public health professionals, and eHealth developers should work together to educate patients about searching for health information online and to provide tools for them to navigate to the highest quality information.*(J Med Internet Res 2002;4(2):e7)* doi:[10.2196/jmir.4.2.e7](https://doi.org/10.2196/jmir.4.2.e7)**KEYWORDS**

Internet; patient education; communication; health status

Introduction

Health information on the Internet is pervasive with thousands of Web sites, chat rooms, and support groups [1]. Some in the medical community have espoused the potential positive impact of the Internet on increasing health education and promoting self-care [2-4]. Others have cautioned about the public health risks of the varying quality of health information [5-8]. Despite these potential risks, millions of Americans have used the Internet to search for health information [9]. A previous survey using a convenience sample of primary care patients at one hospital-based practice suggests that most users rate the quality of Internet-based health information equivalent to information from their doctor [10]. Education of the public about how to evaluate the quality of the health information online is needed [11-13].

Users of Internet-based health information tend to reflect the higher-income, higher-education status associated with having Internet access [10]. However, little else is known about individuals who are searching for health information on the Internet. Are they mostly individuals with poor health and/or current illnesses (ie, our patients), or well individuals looking to stay well? Also, do the experiences online of patients with poor health differ from those without disease (eg, are sicker patients searching for different information, participating in support groups more often)? Answering these research questions may help physicians better understand what their patients are doing and may help public health practitioners better target their educational strategies about health information online.

To answer these questions, we took advantage of data collected in a national random-digit telephone survey by the Pew Internet & American Life Project related to use of health information

online. Our objectives were to explore (1) Internet use characteristics of, (2) types of information sought by, and (3) impact of the Internet health information on the health care experience of individuals with poorer health (ie, fair/poor health) compared with those who reported better health.

Methods

Study Design

To obtain a representative sample of Americans who use the Internet, a national survey was conducted by the Pew Internet & American Life Project using a random-digit sample of telephone numbers selected from telephone exchanges in the continental United States. Between March and July 2000, Princeton Survey Research Associates conducted telephone interviews with Internet users 18 and over. Among these, 2027 individuals who used Internet-based health information were identified using the question, "Please tell me if you ever do any of the following when you go online - look for health or medical information?"

In August 2000, a follow-up telephone survey focusing on Internet health information use was conducted. After approximately 500 interviews were completed with individuals who had previously reported looking for health or medical information, recruitment was closed. While collecting this sample, an additional 144 individuals who participated in the original survey declined to participate. Data from the baseline and follow-up telephone interviews were stripped of unique identifying information for analysis. The Pew data are publicly available for download [14] and the authors received assistance in understanding the sampling frame and data structure from Susannah Fox at the Pew Internet & American Life Project and Jonathon Best of Princeton Survey Research Associates. The database included age, gender, race, education, income, a global rating of health status, patterns of Internet use, types of information searched and the impact of Internet health information on their knowledge and on their health care experience.

Assessment of Health Status (Primary Independent Variable)

Our primary variable of interest, self-reported global health status, was based on a single question, "In general, how would you rate your own health — excellent, good, only fair, or poor?" Single global ratings of health status such as this have been recommended to reflect the wide variation in values of individuals and are in some respects superior to more complex measures [15,16]. A similar-format single-question global health rating is included on the SF-36, the National Health and Nutrition Examination Survey, and the Behavioral Risk Factor Surveillance System [17]. Single-item self-rated health status, or health-related quality of life, is as valid and reliable as more complex measurements and has been highly correlated with many diseases and health outcomes in previous studies [16,17]. Thus, individuals with global health ratings of fair or poor are likely to have chronic disease or acute medical illnesses and higher mortality [17-19].

Patterns of Internet Use, Type of Health Information, and Impact

To assess patterns of Internet health information use, participants were asked when they started using the Internet, how frequently they used the Internet to look for advice or information about health or health care, and the number of Web sites they visited the last time they went looking for health information. Participants were also asked if they believe the information they see on the Internet, if they participated in online chat rooms and whether they were looking for health information online for themselves or someone else. The type of information searched, such as general health information, information about fitness or nutrition, or specific information on a health condition, doctor, or hospital was assessed. The impact of Internet health information on knowledge was assessed by asking if participants had learned anything new from the online health information. Participants were then asked if the health information "has improved the way you take care of your health." Because Internet health information may have an impact on the physician-patient relationship, the survey also included the question, "Did you later talk to a doctor or nurse about the information you got online?"

Analysis

First, demographic characteristics including age, gender, race, income, and education were compared among those with health status ratings of excellent, good, and fair/poor using Mantel-Haenzel χ^2 trend statistics. To compare our sample of Internet users with other patient surveys, the percentages of individuals with fair or poor health status and associated demographic characteristics in this sample were compared with the percentages noted in the year 2000 Behavioral Risk Factor Surveillance System (BRFSS) [20].

The patterns of demographic characteristics associated with global health status in our study were used to confirm the reliability of this measure compared with previous studies. Health status rating has been associated with education, age, and income in previous research [17,21,22].

The frequency of those with fair/poor, good, and excellent health status reporting each pattern, type of information, and impact variable described above was compared using Mantel-Haenzel χ^2 trend statistics [23]. Responses to questions related to pattern of Internet use were dichotomized based on distribution of responses for use as dependent variables in logistic regression. For variables associated with health status in univariate analysis at $P \leq .2$, a series of logistic regression analyses were used to assess the association of our primary independent variable, health status, with each of the dichotomized pattern, type of information and impact dependent variables after adjustment for demographic characteristics. Each model was developed by introducing variables individually and then in combination to assess for evidence of interaction. To test for significance of trend across health status categories, health status was incorporated into the models as a continuous variable. The Pearson χ^2 statistic was calculated for each multivariable model to test goodness of fit, and area under the Receiver Operating Characteristics curve (c statistic) was also calculated to assess

discriminative power [23,24]. Pearson $\chi^2 P > .1$ indicates an adequate fit of the model to the data.

Results

Our sample of 521 Internet users who access health information online identified from this national survey were mostly female (N = 331 [64%]) and had a median age of 42 years. Only 38 individuals (7%) were African American, 5 were Asian, and 20 were other nonwhite races. Compared with the original sample of 2027 Internet health information users, the 521 individuals who agreed to the follow-up survey were similar in ethnic distribution, educational level, and their frequency of Internet

use, but those who completed the follow-up were slightly older (median age 42 vs 39, $P < .01$).

Ninety-nine percent (N = 520) of the participants in the focused Internet health information follow-up survey rated their health status. Based on this single-item global health status question, we identified 59 individuals (12%) with fair/poor health, 257 (49%) with good health, and 204 (39%) with excellent health. Associations of health status with demographics are summarized in Table 1. Compared to the 12% with fair/poor health in this sample, a similar 13.5% of the respondents to the 2000 BRFSS, reported fair or poor health. However, only 28% of individuals in the BRFSS were college graduates compared with 46% in our sample; and 33% of BRFSS participants had household incomes over \$50,000 compared with 48% in our study.

Table 1. Demographic characteristics by health status among Internet health information users*

	N* (%)	Health Status		
		Excellent (%)	Good (%)	Fair/Poor (%)
Overall	521	204 (39)	257 (49)	59 (12)
Gender				
Male	189 (36)	69 (34)	95 (37)	25 (42)
Female	331 (64)	135 (66)	162 (63)	34 (58)
Race				
White	437 (87)	171 (88)	216 (86)	50 (88)
Black	38 (8)	13 (7)	20 (8)	5 (9)
Other	25 (5)	9 (5)	14 (6)	2 (5)
Age				
18-34	149 (29)	60 (29)	177 (30)	12 (20)
35-54	297 (54)	114 (56)	150 (58)	33 (56)
55 and older	74 (14)	30 (15)	30 (12)	14 (23)
Education†				
Less than college	272 (54)	93 (47)	136 (54)	43 (75)
College graduate	233 (46)	103 (53)	116 (46)	14 (25)
Income‡				
Less than \$30,000	154 (30)	54 (26)	73 (28)	26 (44)
\$30,000-\$50,000	117 (22)	39 (19)	65 (25)	13 (22)
Over \$50,000	250 (48)	111 (54)	119 (46)	20 (34)
Married				
Yes	343 (32)	139 (29)	167 (34)	37 (35)
No	161 (68)	57 (71)	84 (66)	20 (65)

* Total N varies slightly due to small number of missing values (less than 2%).

† Mantel-Haenzel χ^2 test for trend $P < .01$.

‡ Mantel-Haenzel χ^2 test for trend $P < .05$.

Health Status and Patterns of Internet Use

A significant dose-response association was seen with shorter history of Internet use and lower health status (Figure 1). Compared with those in excellent health, those with fair/poor health and those with good health were less likely to have begun

using the Internet over a year ago after adjusting for education, age, and income in multivariable logistic regression — see OR (odds ratio) and CI (Confidence Interval) data in Table 2: OR is 0.5 (95% CI, 0.2-1.00) and 0.6 (95% CI, 0.4-0.9) for fair/poor health and good health respectively; P for trend $< .01$.

In contrast, there was a stepwise trend toward more-frequent current use of the Internet for health information among those with poorer health. Those with fair/poor health status were more likely to participate in online chat rooms compared with those

with excellent health, but were less likely to have looked for health information for someone other than themselves (Figure 1, Table 2).

Table 2. Multivariable analyses of health status and Internet use patterns, types of information sought, and impact on health care communication among Internet health information users*

	Health Status	Adjusted Odds ratio†	Goodness of fit	
			Pearson's χ^2	c
Used the Internet over a year ago‡	Excellent	Referent	0.2	0.6
	Good	0.6 (0.4-0.9)		
	Fair/Poor	0.5 (0.2-1.00)		
Use the Internet to look for health information about once a week§	Excellent	Referent	0.2	0.6
	Good	1.54 (1.01-2.37)		
	Fair/Poor	1.77 (0.91-3.41)		
Searched for health information for a child, parent or someone else‡	Excellent	Referent	0.7	0.7
	Good	0.3 (0.3-0.6)		
	Fair/Poor	0.2 (0.1-0.4)		
Participated in online support group for people who are concerned about the same health issues	Excellent	Referent	0.7	0.6
	Good	0.7(0.4-1.4)		
	Fair/Poor	2.3(1.0-5.6)		
Used online chat rooms‡	Excellent	Referent	0.3	0.7
	Good	1.82 (1.1-2.0)		
	Fair/Poor	2.7 (1.3-5.5)		
Sought information about specific doctors, or hospitals‡	Excellent	Referent	0.4	0.6
	Good	2.2 (1.1-4.8)		
	Fair/Poor	3.2 (1.2-8.9)		
Sought information about medicines or treatments for an illness or conditionSECT	Excellent	Referent	0.3	0.6
	Good	1.5 (0.9-2.4)		
	Fair/Poor	2.2 (1.1-4.5)		
Discussed Internet information with Physician or Nurse?‡	Excellent	Referent	0.2	0.6
	Good	1.2 (0.8-1.8)		
	Fair/Poor	3.3 (1.8-6.3)		

* Total N varies slightly due to small number of missing values (less than 2%)

† Logistic regression models developed for each Internet information "pattern/type/impact" characteristic associated with health status at $P \leq 0.2$ in univariate χ^2 . Each adjusted odds ratio is from a separate logistic regression analysis with dichotomized Internet information "pattern/type/impact" characteristic as dependent variable and with health status as the primary independent variable, adjusted for income, age, education.

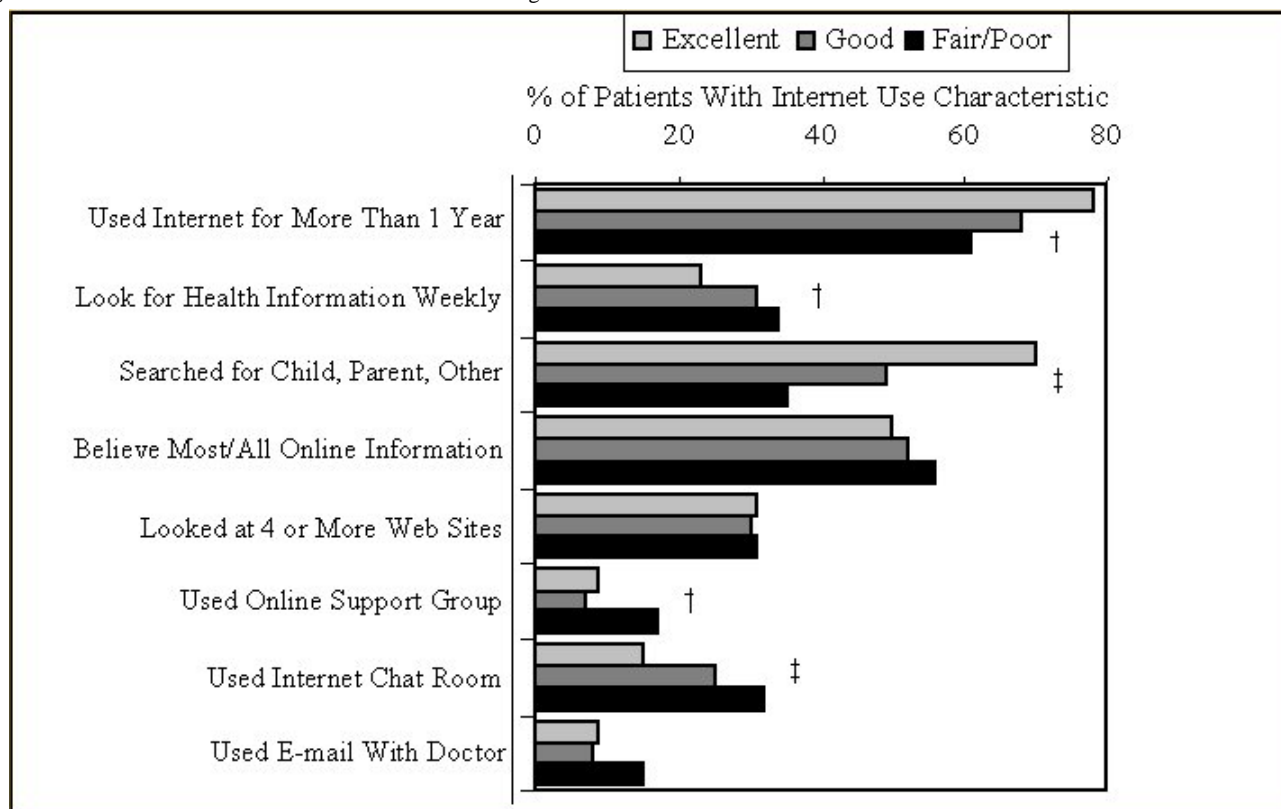
‡ Test for trend $P < .01$.

§ Test for trend $P < .05$.

The majority (52%) of these 521 Internet health information users indicated that they could believe most of the information on the Internet and this did not differ by health status. Only 30% had visited more than 4 Web sites the last time they searched

for health information and this did not differ by health status. Few individuals (N = 49 [9%]) were using e-mail with their doctors (Figure 1).

Figure 1. Health status and Internet use characteristics among Internet health information users

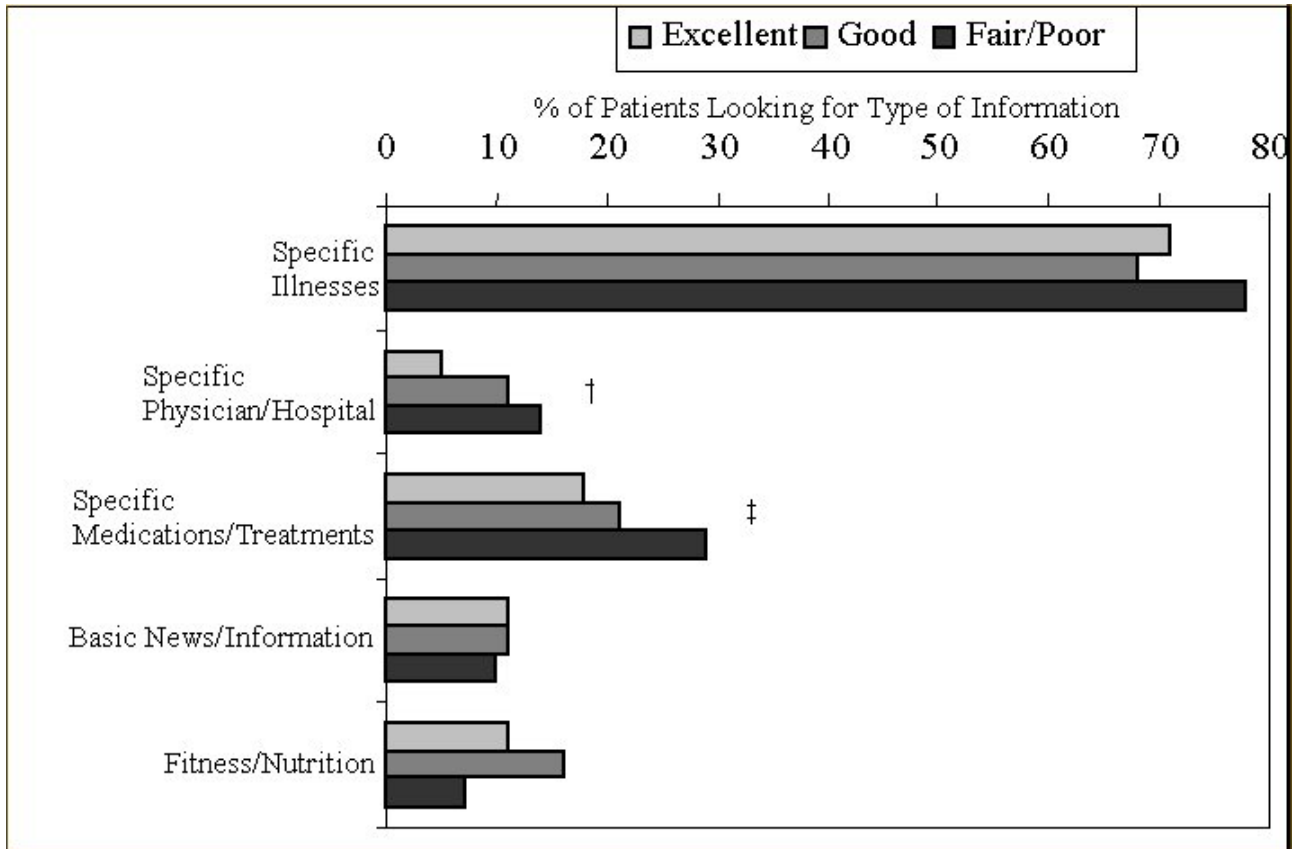


Type of Information Searched

Participants were asked to describe the information they were looking for the last time they went online for health information (Figure 2). A consistent, stepwise association of lower health status with more frequent reporting of searching for information

about specific physicians, hospitals, medications, and treatments was seen. All groups frequently reported looking for information about specific illnesses. In multivariable analysis, those with poorer health status were again more likely to be searching for specific health information the last time they went online (Table 2).

Figure 2. Health status and type of information searched among Internet health information users

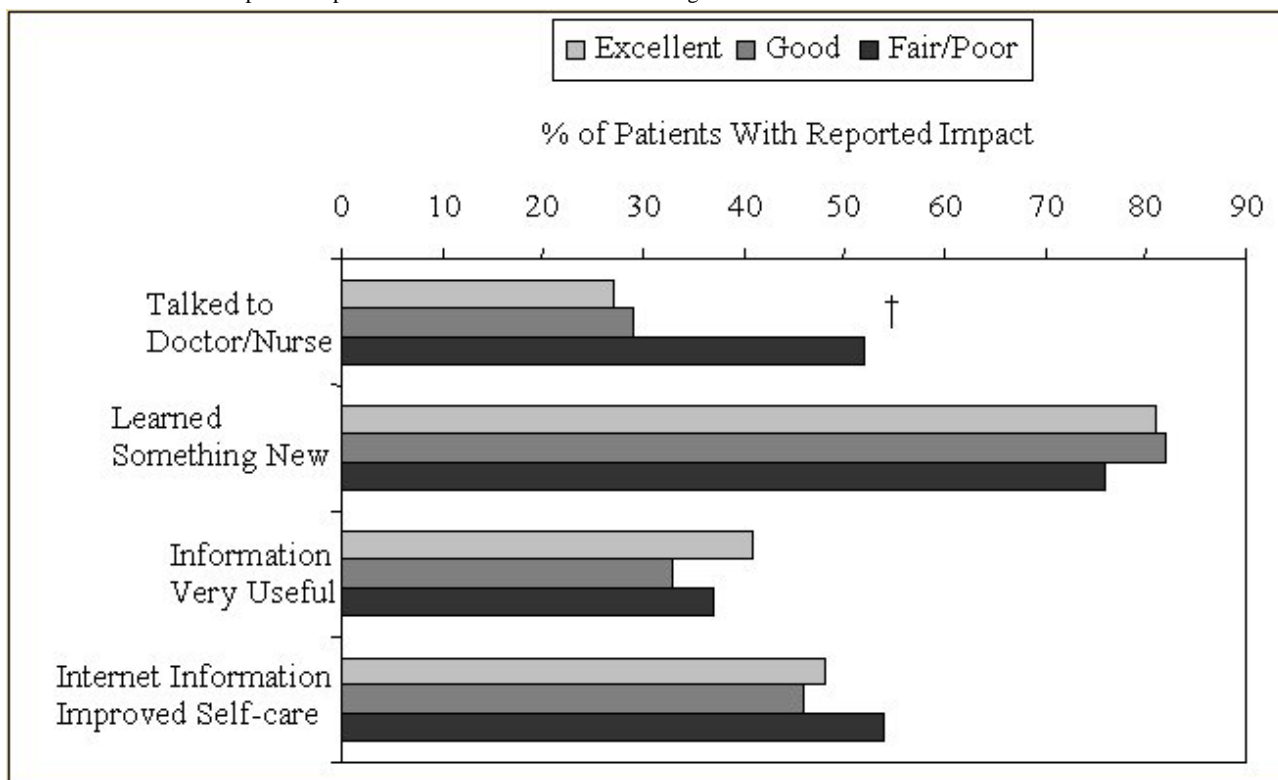


Impact of Internet Health Information

Most individuals (N = 420 [81%]) indicated that they "learned something new" the last time they went online (Figure 3). This report of increased knowledge did not seem to vary by health status. Health status was not related to the self-reported usefulness of the Internet health information. However, the majority (52%) of the 59 individuals with fair/poor health status

reported later talk to a doctor or nurse about the Internet health information, whereas less than a third of those with higher health status reported talking to a doctor or nurse. After adjustment for age, gender, and education, those with fair/poor health were considerably more likely to communicate with a health care provider (OR 3.3 [95% CI, 1.8-6.3]) compared with those with excellent health (Table 2).

Figure 3. Health status and reported impact of online health information among 520 Internet health information users



Discussion

In this telephone survey of 520 current Internet health information users, the majority of individuals reported that they learned something new and trusted the information they found. Consistent with our results, prior surveys of primary care patients using the Internet for health information also suggested that most users rate the quality of information as very good or excellent [10]. Our analysis also provides new data that significant differences exist between sicker patients and those with better self-reported health status in that sicker patients were more-frequent users of Internet health information, more likely to search for specific information, more frequently participating in chats, and more likely to discuss the information they found online with their health care provider.

Main Findings

Over half (52%) of the individuals reported that they could believe all or almost all the information online, but a minority (30%) reported "comparison shopping" for information by looking at multiple Web sites to gather information the last time they went foraging for health information. This provides further evidence that additional public health strategies should be developed to teach users about the variation in quality of information and to help them find quality online information. The majority (80%) of our 520 health information seekers found the information through a search engine. The effectiveness of searching through a search engine is limited, with only 20% of the top links leading to relevant content [8]. Although quality information does exist on the Internet, one systematic review indicated that 24% of the clinical elements felt important by experts were not included in the Web sites found by major search engines [8]. Some Web sites have begun to voluntarily

comply with standards of ethics and quality [25]. Current research aims to develop digital quality seals that can be assigned by third-party raters and help consumers navigate to the best information [26,27]. Efforts to evaluate Web sites and accredit those who meet standards are also ongoing [28,29].

Those with fair/poor health were more likely to search for specific information on their doctor and medications and were more likely to speak to their health care provider about the information they found online. Providers should anticipate that their patients with chronic illnesses may present with information from the Internet. Because the sicker patients were relative newcomers to the Internet and currently frequently used the Internet to find health information, they may be particularly at risk for accessing less than optimal-quality health information. Physicians are a particularly valued source of information for patients and thus the office visit may be an excellent opportunity to educate patients about the variable quality of health information available and to direct patients toward higher-quality information. Thus, physicians should also be educated about Internet-based health information so they may better teach their patients.

The global health status assessment used in this study was reliable when compared to previous studies. The pattern of demographics associated with lower health status, suggests that the health status variable is functioning as seen in previous studies [21,22]. Also, the percentage of individuals with fair or poor health in this study was similar to that seen in the Behavioral Risk Factor Surveillance System [20]. Participants in our sample did vary from those in the BRFSS in that they were more educated and from a higher socio-economic status. It is possible that other chronically ill patients with lower socio-economic status would be motivated to search for health

information online but do not have access to the information due to the disparities in Internet access.

The demographics of many sicker patients (ie, lower income and lower education) identified in this and other research may make those with chronic disease particularly vulnerable to the disparities in access and barriers to understanding the various health Web sites [30]. In addition to the limits of access due to the "digital divide," health literacy also limits access to online health information [8,30]. Further research is needed to extend Internet access to those on the wrong side of the digital divide and to expand the range of Web sites for those with lower health literacy [31-33].

Strengths and Limitations

Our study has several limitations. The survey did not record specific diseases. Although consistent with prior studies, it is possible that using the measure of health status as a surrogate for illness and chronic disease has resulted in some misclassification [21,22]. In addition, the exact Web sites, chat rooms, and search engines that individuals were visiting were unknown. This study is a cross-sectional assessment and inferences of causality cannot be made. Our project focused on current Internet information seekers and is thus not generalizable to individuals who are not currently using the Internet for health information.

A strength of this study is the random-digit, population-based method used to identify this group of users. This increases the likelihood that our sample is representative of the population of Internet users, and thus enhances generalizability. Although this method of sampling misses individuals without telephones, we think it unlikely that many households without telephones have Internet access. Based on a search of the National Library of Medicine's PubMed database as of June 2002, the current study is the first to assess the particular patterns, type of information, and impact of online health information on those

with poor health status. Previous research on use of the Internet among patients has been based on convenience samples [10]. In addition, the level of detail within this exploratory analysis provides pilot data on which to build future research related to tailoring information to the health information needs of those with poor health status.

Conclusion

Our study provides preliminary data on the experiences of online health information seekers. Although the majority of participants were in good health, those individuals with apparent illnesses were more-frequent users of the health information, and were more likely to combine their information seeking with their health care experience. Because the sicker patients are frequent users of specific Internet health information, they may be a population especially vulnerable to the varying availability and quality of Internet health information.

Very few individuals had used the Internet as a portal to communicate with their health care providers, but those with fair/poor health were more likely to communicate in person with their health care providers about the Internet health information they found. Thus, health care professionals should be aware that their patients with lower health status who have used the Internet for health information are likely the ones to come to them to discuss the information they have found. When presented with health information from the Internet, physicians can use this as a "teachable moment" and take the opportunity to educate their patients about the variability of information quality, and point patients toward appropriate sites. Physicians, public health professionals, and eHealth developers should work together to educate patients about searching for health information online and to provide tools for them to navigate to the highest quality information. Future studies should prospectively assess the impact of Internet-based health information on health care utilization and outcomes.

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Conflicts of Interest

None declared.

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Abbreviations

BRFSS: Behavioral Risk Factor Surveillance System

OR: Odds Ratio

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Original Paper

Smoking Cessation and the Internet: A Qualitative Method Examining Online Consumer Behavior

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Abstract

Background: Smoking is a major preventable cause of disease and disability around the world. Smoking cessation support — including information, discussion groups, cognitive behavioral treatment, and self-help materials — can be delivered via the Internet. There is limited information about the reasons and methods consumers access smoking cessation information on the Internet.

Objectives: This study aims to determine the feasibility of a method to examine the online behavior of consumers seeking smoking cessation resources. In particular, we sought to identify the reasons and methods consumers use to access and assess the quality of these resources.

Methods: Thirteen participants were recruited via the state-based Quit® smoking cessation campaign, operated by the Victorian Cancer Council, in December 2001. Online behavior was evaluated using semi-structured interviews and Internet simulations where participants sought smoking cessation information and addressed set-case scenarios. Online interaction was tracked through pervasive logging with specialist software.

Results: Thirteen semi-structured interviews and 4 Internet simulations were conducted in January 2002. Participants sought online smoking cessation resources for reasons of convenience, timeliness, and anonymity — and because their current information needs were unmet. They employed simple search strategies and could not always find information in an efficient manner. Participants employed several different strategies to assess the quality of online health resources.

Conclusions: Consumer online behavior can be studied using a combination of survey, observation, and online surveillance. However, further qualitative and observational research is required to harness the full potential of the Internet to deliver public health resources.

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KEYWORDS

smoking cessation; Internet; health behavior; health promotion

Introduction

"Every eight seconds a person dies of a tobacco-related disease and almost as quickly another victim is recruited." [1]

The World Health Organization (WHO) attributes about 4 million deaths a year to tobacco use, a figure expected to rise to about 10 million deaths a year by 2030 [2]. Smoking kills 19000 Australians each year and represents the major

preventable cause of disease and disability in Australia [3]. Tobacco is highly addictive and quitting smoking is the single most important action a smoker can take to improve his or her health [4].

Smoking cessation information and supportive resources such as discussion groups, cognitive behavioral treatments, and tailored self-help materials can be delivered via the Internet. Nicotine-replacement therapies can also be purchased online. In May 2002, it was estimated that almost 10% (580 million)

of the global population have accessed the Internet [5]. In Australia, 50% of Australian adults and 37% of households have Internet access and more than 25% of Australians aged between 15 and 54 years of age seek online health resources [6-7]. Thus the Internet can potentially deliver smoking cessation interventions, resources, and information to a critical mass of consumers.

There are many Web sites concerned with smoking cessation. (For example, using the Google search engine and the terms *stopsmoking* returned 940000 hits and *smokingcessation* returned 247000 hits on February 5, 2002.) Despite the volume of online information, we could not identify any published studies about the quality of online information about self-help smoking cessation. The overall quality of online health information is variable, sometimes fraudulent and misleading [8]. We lack understanding about whether consumers can differentiate between good and poor quality Web sites. Further, we do not know why consumers access online smoking cessation resources in preference to telephone helplines or face-to-face health-professional advice.

This study determines the feasibility of a method to examine the online behavior of consumers seeking smoking cessation information. In particular, we aim to identify the reasons consumers choose to use the Internet to obtain smoking cessation information and how they conduct searches for online information. The results of this project will inform those interested in realizing the full potential of the Internet to deliver smoking cessation interventions and resources to the broader community in a timely, convenient, and economical manner.

Methods

The Victorian Quit® program is the major state agency providing a range of supports to smokers wanting to quit and to health professionals whose roles include encouraging smoking cessation. It produces a range of written materials, most reproduced on its Web site, and has an extensive statewide telephone service. Callers to that service are offered a set of printed cessation resources and/or access to trained cessation counsellors. We recruited a convenience sample of participants for this study from those consumers contacting the telephone helpline who agreed to be contacted for research purposes and via an advertisement placed on the state-based Quit® Web site operated by The Cancer Council Victoria, Australia [9]. We

invited consumers to participate in a semi-structured interview and an online simulation regarding use of the Internet for smoking cessation purposes.

We reimbursed participants Aus \$40 to cover their costs and an additional Aus \$20 if they participated in the Internet simulations. All participants gave informed signed consent and were free to withdraw from the study at any time. Ethics approval was granted from the relevant Southern Health Human Research Ethics Committee, Monash Medical Centre.

We recruited 13 participants in early January 2002. By chance, we recruited all participants via the Quit® Web site and all participants were currently trying to stop smoking. We conducted 13 semi-structured interviews involving 4 males and 9 females, aged 19 to 64 years (median 30-39 years). Twelve participants used the Internet at least once a week and had Internet access at work or home. The amount of time spent online ranged from 30 minutes to 10-12 hours per week. Nine of the 13 participants had obtained a Bachelor of Higher Degree. Two participants lived in non-metropolitan locations. Two participants had total household incomes less than the Australian average gross household income (which is slightly lower than Aus \$40000) [10]. Four of the 13 participants voluntarily chose to participate in the Internet simulations.

We conducted semi-structured interviews (Appendix 1) by telephone or face-to-face, audio-taped, then transcribed. We employed qualitative research methods to collect context-bound data that help to predict, explain, or understand a particular phenomenon. GF employed a framework approach to analyze the interview data (Table 1) [11]. This approach starts deductively (reasoning from general to particular instances) from the aims and objectives set for the study and the results are grounded (heavily based in the original accounts and observations of the people studied) and inductive (employing the process of inferring a principle from the observation of particular instances). Such an approach is advantageous because the analytic process and interpretations can be viewed and assessed by people other than the primary analyst. TB reviewed the resultant themes and conflicting views. Themes were identified using a constant comparison method, whereby each category is searched in the entire data set and all instances are compared until no new categories emerge; a time intensive process.

Table 1. The 5 stages of data analysis using a framework approach

1. Familiarization -- immersion in the raw data by reading transcripts, in order to list key ideas and recurrent themes
2. Identifying a thematic framework -- identify all the key issues, concepts and themes by which the data can be examined and referenced by drawing on prior knowledge, the aims and objectives of the study, and issues raised by participants
3. Indexing -- applying the thematic framework to all the data using codes
4. Charting -- rearranging the data according to themes. The end result is a chart for each key theme containing distilled summaries of participants' views and experiences
5. Mapping and interpretation -- using the charts to define concepts, map the range and nature of the phenomena, create typologies, and find associations between themes with a view to providing explanations for the findings

We used a desktop computer with Internet access to conduct the simulations. We initially asked participants to seek general

online smoking cessation information and secondly asked participants to address 3 set-case scenarios (Appendix 2). We

tracked participants' online interaction through pervasive logging with specialized software (Omniquad Desktop Surveillance Personal Edition ® [12]). This software records the search engines and terms used and the sites visited. It also makes a screen capture every minute, so that the log can be cross-referenced to ensure that the correct site information is recorded. The simulations were observed by a research assistant who also noted the search engines, key phrases, Web sites visited, and any verbal comments made by participants.

Results

General information

Participants most commonly perceived that people found out about ways to stop smoking via television and family or friends. However, they had all sought online smoking cessation information for reasons of convenience. Based upon past personal experiences the participants also felt that there were

benefits of being able to access health information — especially smoking cessation information — anonymously; some felt uncomfortable speaking to health professionals about quitting.

For example, one participant said, " *You don't have to speak to people who make you feel bad.*"

Five participants felt that online health information was preferable to other information sources because it offered a global perspective and the opportunity to find specific information.

All participants self-reported using commercial search engines and none accessed health-specific search engines or portals during the Internet simulations. A variety of search terms were employed, most commonly *quitsmoking*.

Participants sought and found information about many themes upon seeking general information about smoking cessation (Table 2, Table 3).

Table 2. Types of information sought by consumers* (N=13)

Category	Number of responses
Support available	3
General information	3
Weight gain when quitting	2
Support you can offer others	2
Strategies for stopping	2
About Quit REG_ENTITY	1
Nicotine Replacement Therapy	1
Products	1
Dealing with cravings	1
Coping with stress when quitting	1
Total	17

Table 3. Types of information found by consumers* (N = 13)

Category	Number of responses
Stop smoking advice/strategies	7
Support services	5
Sites selling products for quitting	5
Nicotine Replacement Therapy	3
Benefits of stopping	2
Diet plan for quitters	1
Descriptive statistics on prevalence of smoking and related adverse health outcomes	1
Reasons to stop smoking	1
Quit REG_ENTITY course information	1
Personalized calendar	1
Sites selling cigarettes or tobacco products	1
Stress management information	1
Total	29

* Participants could give multiple responses.

Nine of the 13 participants stated that general information about quitting was valuable. In particular, quitting strategies, the benefits of quitting, practical information about weight gain, and stress management when quitting were useful. Six of the 13 participants identified the Australian National Tobacco Campaign Web site [13] as the most useful. The Quit Book® was highlighted as a good source of information. The Quit Book® is an Internet version of an information booklet distributed as the main written resource to callers to the Quitline® telephone advisory service. It provides a staged approach to quitting and provides tips and other advice.

Participants responded positively to the interactive and personalized elements, such as online questionnaires or "quizzes" where they could enter personal information and receive tailored information in response. For example, men would not receive information about smoking in pregnancy. Currently most written health information is "one size fits all." Three of the 13 participants self-reported that this tailored information was valuable.

One participant said, " *You can lose a lot of personal touch by quitting on-line - I looked for sites with a personal touch.*"

Some of the participants also highlighted interactive sites as being useful. In particular, items like quitting guides, calendars, chat rooms, online peer support, and money-saver and years-added-to-life calculators were identified as being valuable.

Most of the participants recommended using the Internet in combination with other support resources including health professionals.

One participant said, " *The internet is a good starter, but you can't ask questions.*"

Accessing alternative support was perceived as an opportunity to cross-check the reliability of the information available on the Internet.

Many participants perceived that the process of determining the reliability or quality of information was difficult and one participant indicated that it was a "very scary" prospect. Despite these uncertainties a range of tactics were identified (Table 4).

Overall, consumers felt that using government Web sites or Web sites associated with a known specialist or reputable organization were the best way to access reliable information. None of the participants checked the about-us or terms-and-conditions information published on Web sites.

Table 4. How consumers assess the reliability of Web sites when seeking smoking cessation information and support* (N = 13)

Consumer assessment	Number of responses
Government sites	6
Web sites associated with known organizations	5
If selling something, suspect site	5
References published	5
Rely on my judgement/common sense	2
Follow friend's recommendations	2
Compare information across sites	1
Cross-check with health professional	1
Visual quality of the Web site	1
Currency of information	1
Medical site	1
Secure site	1
Total	31

* Participants could give multiple responses.

The least-valued items included descriptive statistics about the prevalence of smoking and adverse health effects, repetitive information, and the reasons for stopping smoking.

One participant said, " *We already know that... we hear the information about the damage caused by smoking all the time.*"

One participant searching for information about stress management felt that there were a lot of sites that made the link between smoking cessation and stress, but also felt that there was limited practical information about how to manage the stress.

All but one participant stated that they would recommend people seek smoking cessation information via the Internet. The dissenter would not recommend the Internet, because "there was a lot out there, but they aren't identified in the searches" and furthermore "Australian sites were too difficult to find."

Participants self-reported that the information they found on the Internet prompted them to modify their diet, and to consult health professionals and the state-based Quit® organization. They also self-reported sharing this information with others.

Case scenarios

In the first-case scenario, upon trying to find information about nicotine-replacement therapies and whether patches are more effective than gum, 3 of the 4 participants identified a range of nicotine-replacement-therapy formulations including gum, patches, nasal sprays, and inhalators. The fourth participant was only able to identify gum and patches. None could make judgements about the comparative effectiveness of the formulation types based upon the information published on the 11 Web sites visited. Furthermore, despite the participants expressed desire to seek unbiased information about nicotine replacement therapies, only half the Web sites visited were government or independent sites. The remainder were commercial Web sites selling pharmaceuticals.

In the second-case scenario, overall, participants found it difficult to locate local support services despite the use of multiple search terms. Two participants said that they had found an international Web site that provided users with the opportunity to find their local support services, by entering their postcode. However, they were unable to find this feature on an Australian Web site.

In the third-case scenario, all participants identified that Zyban® (bupropion HCl) was available as a prescription-only medicine and could list the risks or side effects associated with use by accessing information published on the Internet. The manufacturer's Web site was accessed by all. Other Web sites accessed included current-affairs and consumer-affairs Web sites, Quit®, and Web sites selling pharmaceuticals.

Discussion

Participants sought online smoking-cessation resources because they were convenient, timely, and anonymous. However, the quality of online health information is variable and the ranking of Web sites on commercial search engines is often influenced by money, not quality [14]. Despite these issues, consumers value online information and resources but cannot always find the information they need in a timely efficient manner, partly because they utilize simple search strategies and commercial search engines. However, these consumers were unsure how to assess the quality of online health information.

Our results are strikingly similar and directly support those of a recently-published paper examining how German consumers search for and appraise general health information on the Web [15]. However, our study is limited to an examination of the views of a small group of online health seekers who accessed

the Quit® Web site and therefore may not reflect the experiences of the wider community of Australian smokers. Despite this limitation, the study demonstrated that the methodological design was feasible and these results provide a useful starting point to inform future research examining online consumer behavior. We intend to recruit a larger number of consumers for future studies using advertisements placed in Australian metropolitan and rural newspapers, in addition to the Quit® Web site and information packs.

Tobacco is highly addictive and many users are unable to voluntarily cease use, even when aware of the harm tobacco causes. A comparison of the information sought and that found by participants demonstrates that participants were able to access smoking cessation strategies and support services from around the world. However, those participants seeking complementary local resources such as face-to-face support groups or telephone counselling had difficulty locating Australian Web sites to access this information. Thus other types of media such as radio, television, and newspapers are necessary to promote local smoking cessation activities.

Approximately 80% of smokers in Australia have tried to quit at least once [16]. Effective relapse-prevention strategies are of utmost importance, given that most cessation attempts are unsuccessful [17]. Self-help interventions for smoking cessation suggest a modest effect [18] and there is increasing evidence on the effectiveness of computer and Internet mediated systems for the delivery of such interventions [19-21]. This study supports the further development of interactive and personalized smoking cessation tools delivered via the Internet because it demonstrates that consumers control and focus their use of the Internet to areas in which they are interested and need support/information. A randomized controlled trial examining the effectiveness of computer-tailored advice for smoking cessation and relapse prevention is currently being conducted in Australia by Borland R, Balmford J and Hunt D.

Conclusions

Qualitative research can give rise to insights into emerging research areas by allowing us to collect context-bound data. This research demonstrates that the behavior of consumers seeking online health information and resources can be studied using a combination of survey, observation, and online surveillance. However, further qualitative and observational research regarding the online behavior of consumers is required if we are to harness the full potential of the Internet to deliver public health — in particular smoking cessation, interventions, and resources — to society.

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Conflicts of Interest

None declared.

Appendix 1

Semi-structured interview questions

First of all, I'm just going to start with some general questions about your use of the Internet...

- 1. How often do you use the Internet?
- 2. Where do you use the Internet? (e.g. library/home/work)
- 3. Approximately how much time do you spend per week (or month) on the Internet?
- 4. Have you ever searched for health information for other people (e.g. family/friends)?

The next questions relate more to stopping smoking...

- 5. In general, how do people find out about ways to stop smoking and the support services available?
- 6. Have you used the Internet to find out information about stopping smoking and the services available?
- 7. Given there are other ways of finding out about stopping smoking, why do you think people choose to use the Internet to obtain information about quitting?

The next questions are about specific stop smoking information you found on the Internet...

- 8. Before you started searching on the Internet, did you have anything that you wanted to know specifically? Were you expecting to find anything in particular?
- 9. How did you actually search for information about stopping smoking?
- 10. What type of information did you find?
- 11. How do you tell if information on the Internet is reliable?

Next, we are going to discuss the quality of the websites and what happened next for you...

- 12. What did you do with the information that you found?
- 13. How did you use this information?
- 14. What was the most useful/valuable information/item you found on the Internet about stopping smoking? Why was it so valuable?
- 15. What was the least useful information/item that you found on the Internet about stopping smoking? Why?
- 16. Given your experience, if a good friend wanted to stop smoking and they needed information, would you recommend they use the Internet? Why/Why not?

Appendix 2

Internet simulations

Prior to simulation:

Give the participant the opportunity to search generally on the Internet for information about stopping smoking.

Scenario 1

You have heard that Nicotine Replacement Therapy (NRT) doubles your chances of quitting. What types of NRT products are available? Are patches more effective than gum?

Scenario 2

You need help to stop smoking. What are the local support services available in your area? What are the contact details?

Scenario 3

You saw a report on television about Zyban®, a new drug to help people stop smoking. Are there any risks or side effects? Where can you buy it?

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Original Paper

Use of the Internet by Women with Breast Cancer

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Abstract

Background: Recently, many cancer patients have been using the Internet for information with which to make informed choices. We are not aware of any studies that investigate this Internet use among breast cancer patients or women.

Objective: We investigate the prevalence and predictors of Internet use for medical information among women with breast cancer.

Methods: We used a cross-sectional design and approached 251 women with breast cancer being treated at a university-based hospital. We successfully interviewed 188 (74.9%), through mailed self-report questionnaires. Medical information was obtained from the hospital tumor registry. We used t tests and chi-square tests to assess differences in Internet use for breast health issues and binary logistic regression to estimate the odds ratio (OR) for predictors of Internet use for breast health issues.

Results: In our sample, 41.5% of patients used the Internet for medical information. Internet users differed from nonusers on income level, educational level, and by race/ethnicity. After controlling for the other predictors, Internet users had a higher income (OR = 3.10; 95% CI = 1.09-8.85) and tended to be more educated (OR = 2.59; 95% CI = 0.87-7.74) than nonusers. There was also a suggestion that those of nonwhite ethnicity were less likely to use the Internet (OR = 0.39; 95% CI = 0.14-1.11). Increasing age, length of time since diagnosis, and breast cancer stage had no effect.

Conclusions: A substantial proportion of breast cancer patients used the Internet as a source of information. Patients with higher income or education, and patients of white race/ethnicity are more likely to use the Internet for breast health issues.

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KEYWORDS

breast cancer; communication; decision-making; information; Internet

Introduction

Physicians have traditionally been the sole providers of information to patients about their diagnosis, prognosis, and treatment options. Until recently, many physicians believed that patients could not cope with bad news and should be kept ignorant of many details about their illness [1].

Many patients no longer feel comfortable with this paternalistic approach and are becoming more insistent about being fully informed and participating in their treatment decision-making. Some studies of cancer patients indicate patient preferences for knowing as much as possible, ranging from 79% to 96% [2-6]. These information seekers tend to be of higher socioeconomic status, younger age, and white race/ethnicity [2,4] and are more

hopeful about their prognosis [2,7]. Those in the US are more likely to seek information in a variety of areas than those from the UK [8].

Cancer patients are often dissatisfied with the information provided to them. One study showed that only 19% of 232 patients were satisfied with the information they received from their physicians [9]. Studies done specifically with breast cancer patients show that many want to have a collaborative role with their physician in major treatment decisions [10,11] and many desire more detailed information [12].

Patients use the Cancer Information Service (National Cancer Institute; <http://cis.nci.nih.gov/>), print literature, television, and radio for information [13,14]. Whites are more likely to rely on books, while African-Americans are more likely to use television and radio programs as sources of information [14]. One new source of cancer information is the Internet. It is widely available; individuals can access it at work, home, and their local libraries. Physicians themselves are increasingly using it for information [15,16]; 20% consider its use essential to their duties as a physician [17].

Although there are potential risks for use of the Internet because the information is unmonitored [18-20], patients are increasingly turning to it for information. A 1997 survey in the US found that nearly half of Internet users spent some time looking for health information on the Internet [21]. In the US in 2000, 41 million individuals [17] and — a survey conducted in the US in March 2001 suggested — 100 million individuals [22] were estimated to have sought health information on-line. Patients report that Internet use often keeps them more informed than the doctors to whom they go for treatment [23]. Cancer is 1 of the top 3 diseases about which the public seeks information on the Internet [24].

Few studies have explored the use of the Internet by cancer patients and — to our knowledge — below are reviewed all the studies. One qualitative study evaluated a computer-based cancer-support network for individuals coping with cancer [25]. The only demographic characteristics mentioned were gender and marital status. Another qualitative study evaluated participants of an on-line breast cancer listserv [26] and did not provide the demographic characteristics of the participants. A Swedish study of 142 cancer patients found that only 8 (6%) used the Internet for information [27]. A recent Canadian descriptive study of mixed-diagnosis cancer patients found that 51% searched the Internet for medical information [28]. Another recent study discussed Internet use by prostate cancer patients and found users more likely to be younger, more educated, to own a personal computer, and to have prior experience with computers [29]. A recent preliminary Norwegian study of 31 cancer patients found that 4 (13%) used the Internet for medical information. These Internet users were slightly younger than nonusers were [30].

This is the first study that we are aware of both breast cancer patients and women who use the Internet for medical information. We investigate the prevalence and predictors of Internet use by women with breast cancer for information related to breast health issues.

Methods

The participants for this study were patients seen by 2 breast surgeons at Columbia Presbyterian Medical Center, a university-based hospital in New York City. Inclusion criteria included age < 65 years and a diagnosis of ductal carcinoma in situ (DCIS) or invasive breast cancer within 3 years. All patients who met these criteria were invited to participate. Participants with a prior psychiatric/substance abuse history or who did not speak English were excluded. Institutional review board approval was obtained.

Participants were identified from hospital tumor-registry records. Potential participants were mailed a letter describing the study along with a postal card to return if they were not interested in participating. Those who did not return the postal card were called and the nature of the study described. Those who agreed to participate were mailed a packet with a questionnaire containing demographic and Internet-use questions. The Internet-use questions asked participants to circle *yes* or *no* to the question, "Do you use the Internet?" If *yes*, they were asked to circle locations of use (home, work, library, friend). For our study, we defined Internet use as World Wide Web use for information regarding breast health/women's health issues. We determined such use by asking participants to circle *yes* or *no* to the question, "Do you use the world wide web?" If *yes*, they were asked, "Do you use it for information regarding breast health/women's health issues?" See [Appendix](#) for the Internet use questionnaire used in this study.

A postage-paid envelope was provided. If necessary, two follow-up phone calls were made to remind participants. We approached 251 individuals (including 18 who initially declined, 25 who declined after any of the phone calls, and 20 who did not return their questionnaires). Of the 251, 188 (74.9%) chose to participate. Medical information was obtained from hospital tumor-registry records. All data collection took place from October to December 2000. Informed consent was obtained.

Data Analysis

Our analyses compared users with nonusers of the Internet for breast health issues. T tests for independent samples were used to evaluate differences for continuous demographic variables and chi-square analyses assessed group differences for categorical variables. All categorical variables were dummy coded for inclusion in a regression analysis. African-Americans and Hispanic-Americans were combined into nonwhites in the race/ethnicity category for all analyses. The 7 Asians and 1 unidentified in the race/ethnicity category were excluded from the regression analysis due to their small number. The primary analysis used binary logistic regression to determine odds ratios for Internet use, controlling for the other predictors. All *P* values were 2-sided. All analyses were done with SPSS (Version 9) [31].

Results

[Table 1](#) describes the characteristics of users and nonusers of the Internet (ie, World Wide Web) for breast health. In our

sample, 41.5% used the Internet. Sources of Internet use were at home (53.7%), at work (35.1%), at a friend's house (5.9%), and at a library (5.3%). With univariate analyses, Internet users

were more educated, of higher income, more likely to be white, had a trend to be younger, and differed neither in breast cancer stage nor in length of time since their cancer diagnosis.

Table 1. Characteristics of 188 women with breast cancer*

Demographic Variable	Category	Web Use Mean (SD) / # (%) (N = 78)	No Web Use Mean (SD) / # (%) (N = 110)	Significance (P)‡
Age (years)		50.21 (7.69)	52.35 (8.71)	.08
Time since diagnosis (years)		1.75 (0.80)	1.93 (0.81)	.13
Annual household income	< \$60,000	9 (12.7%)	36 (37.5%)	.001
	\$60,000-\$100,000	26 (36.6%)	30 (31.3%)	
	> \$100,000	36 (50.7%)	30 (31.3%)	
Education	Grades < 12	9 (11.5%)	35 (32.1%)	.004
	Grades 13-16	35 (44.9%)	40 (36.7%)	
	Grades > 16	34 (43.6%)	34 (31.2%)	
Race/ethnicity	White	66 (86.8%)	77 (74.0%)	.04
	Nonwhite	10 (13.2%)	27 (26.0%)	
Stage	DCIS	19 (24.7%)	25 (22.9%)	.96
	Stage 1	32 (41.6%)	47 (43.1%)	
	Stage 2-3	26 (33.8%)	37 (33.9%)	

* From interviews at Columbia-Presbyterian Medical Center, October 2000 to December 2000, regarding Internet (World Wide Web) use for breast health issues. Not all variables have the total N = 188 since not everyone responded to all the items on the self-report measures. P values were calculated with t tests for the means and chi-square tests for the percentages.

Table 2. Predictors of Internet use of 188 women with breast cancer*

Demographic Variable	Category	OR‡	95% CI†	Significance (P)
Age (years)		0.97	0.92-1.02	.19
Time since diagnosis (years)		0.73	0.46-1.15	.18
Annual household income	< \$60,000	1.00		
	\$60,000-\$100,000	2.81	1.00-7.91	.05
	> \$100,000	3.10	1.09-8.85	.04
Education	<Grades < 12	1.00		
	Grades 13-16	2.92	1.00-8.54	.05
	Grades > 16	2.59	0.87-7.74	.09
Race/ethnicity	White	1.00		
	Nonwhite	0.39	0.14-1.11	.08
Stage	DCIS	1.00		
	Stage 1	0.94	0.38-2.34	.89
	Stage 2-3	1.95	0.73-5.21	.18

* From interviews at Columbia-Presbyterian Medical Center, October 2000 to December 2000, regarding Internet (World Wide Web) use for breast health issues. Not all variables have the total N = 188 since not everyone responded to all the items on the self-report measures. Logistic regression analysis performed, controlling simultaneously for the other predictors above.

‡ OR indicates odds ratio

† CI indicates confidence interval

Table 2 shows the results of logistic regression analysis, controlling for the other predictors. The model was significant ($\chi^2 = 27.67$, $P = .001$). As can be seen, income level remained

significantly related to Internet use, as did increased educational level. Those with an income level > \$60,000 were 3 times more likely to use the Internet than people with incomes < \$60,000.

Patients with a college education (ie, those in the groups of grades 13-16 and > grade 16) were almost 3 times more likely to use the Internet than those with a high school education or less. Nonwhite patients were less likely to use the Internet than whites, but this did not reach statistical significance. Age, length of time since diagnosis, and breast cancer stage were unrelated to Internet use.

Discussion

Internet use is popular among breast cancer patients. Over 40% of our sample used it for breast health issues. In addition, our results are consistent with the prior literature suggesting that higher income and race/ethnicity are associated with patient information seeking [2,4,14].

We found that increased income and educational level were significant predictors of Internet use. Individuals with these characteristics may have been exposed to newer technology and have the comfort level to experiment with Internet use. They also may be more likely to use the Internet as part of their daily work. Race/ethnicity is related to Internet use where whites use the Internet more than nonwhites do.

In a study of Internet use by patients with prostate cancer [29], income level was not assessed. Our study shows that income level is strongly associated with Internet use and is a significant predictor of use of the Internet by patients with serious illnesses.

In our study, age, length of time since diagnosis, and breast cancer stage were not significant predictors of Internet use. The absence of an age effect in our study may differ from other studies of information use because we excluded those > 65 years from the study. Our results have adequate sample size and answer many of the preliminary questions of Norum [30].

The strengths of our study include the high participation rate and the inclusion of those with different stages of disease. However, we relied on self-report and did not have a way of independently validating the reported use. Our sample included those of multiethnic populations. However, these results would

be strengthened by having a greater percentage (eg, 50%) of participation by those from multiethnic populations.

Internet use may have clinical relevance. Eakin and Stryker [32] showed that 70% of physicians refer their cancer patients to various support services. Patient use of these services is quite low, ranging from 2% to 8%. Of those patients aware of Internet-based cancer information services, which they found to be 14%, one half (7%) used it. Many patients may find it more comfortable to seek information over the Internet than to use traditional cancer support services.

The generalizability of these findings may be limited to those with early-stage breast cancer, women < 65 years, higher income, higher education, and those with a diagnosis of almost 2 years. Although not deliberately screened out, there were no patients with stage 4 breast cancer. It is possible that many of these late-stage patients died during the time interval from diagnosis to study completion or refused to participate. For those recently diagnosed, improved mammography screening rates allow many to be diagnosed with an early-stage rather than a late-stage cancer. Furthermore, the participants were only selected from 2 surgeon's practices and the income and education may be higher than those with breast cancer in the general population in the US. This may limit the generalizability of this study and future studies should include other hospitals/health centers to determine if these results could generalize to all breast cancer populations in other regions or countries.

Longitudinal research should investigate Internet use among various stages and times since diagnosis among breast cancer patients. Time sampling of Internet use at various intervals in an objective manner can improve these self-report results. As elderly women become more comfortable with Internet use, their use should be studied. More knowledge is needed about the quality of the Web sites used, the types of information sought, and the involvement of Internet use for patient decision-making. Research should evaluate if patients and/or physicians feel there are potential clinical benefits for this Internet use. Part of the work reported in references [33-35] is based on information from the questionnaire in the [Appendix](#).

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Conflicts of Interest

None declared.

Appendix 1

Internet Use Questionnaire [[DOC File, 28KB](#) - [jmir_v4i2e9_app1.doc](#)]

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Abbreviations

CI: Confidence Interval

OR: Odds Ratio

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Review

A Review of Features in Internet Consumer Health Decision-support Tools

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Abstract

Background: Over the past decade, health care consumers have begun to benefit from new Web-based communications tools to guide decision making on treatments and tests. Using today's online tools, consumers who have Internet connections can: watch and listen to videos of physicians; watch and hear the stories of other consumers who have faced the same decisions; join an online social support network; receive estimates of their own chances of experiencing various outcomes; and do it all at home.

Objective: To review currently-available Internet consumer health decision-support tools.

Methods: Five Web sites offering consumer health decision-support tools are analyzed for their use of 4 key Web-enabled features: the presentation of outcomes probability data tailored to the individual user; the use of videotaped patient interviews in the final product to convey the experiences of people who have faced similar diagnoses in the past; the ability to interact with others in a social support network; and the accessibility of the tool to any health care consumers with an Internet connection.

Results: None of the 5 Web sites delivers all 4 target features to all Web users. The reasons for these variations in the use of key Web functionality — features that make the Web distinctive — are not immediately clear.

Conclusions: Consumers trying to make health care decisions may benefit from current Web-based decision-support tools. But, variations in Web developers' use of 4 key Web-enabled features leaves the online decision-support experience less than what it could be. Key research questions are identified that could help in the development of new hybrid patient decision-support tools.

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KEYWORDS

decision making; informatics; Internet; multimedia; social support; treatment outcome; prognosis

Introduction

A Decade of Development of Decision-support Tools

If, 10 years ago, health communicators had learned that they could deliver programs to peoples' homes on demand, with video, data tailored to the individual user, and with a social support network in place through these programs, many may have jumped at the opportunity. Today all of that can be done through the use of the Internet. However, while it is possible that this research overlooked a new Web site, I did not find any current health-related Web site that offers consumer health decision-support tools using all of the Web features described.

Since the early 1990s, there has been an evolution in development of patient-targeted decision-support tools in different media: printed materials, videotapes, CD-ROMs,

computer-based interactive multimedia (laserdisc) programs, and Web-based programs [1]. A 1997 report by the Agency for Health Care Policy and Research stated: "Although patient health informatics tools can potentially empower patients to make more informed choices, there is limited empirical evidence of the outcomes of their use and of their overall value." [2] Since then, reviews of trials of decision aids [3] and of the potential impact of such tools on clinical practice [4] have been published. Meager though such outcomes evaluation may be, it may nonetheless outpace the formative and process evaluation in the development of such tools. Perhaps because many of the development efforts are conducted behind the walls of proprietary ventures, there is little public information available on the development of Internet consumer health decision-support tools. This review analyzes 4 areas of variability in the use of key Web-enabled features in online decision-support tool development. The features in question are some of the key

functionalities that distinguish the Web from other media. No other medium can deliver the combination of these 4 features.

Web-enabled Features

1. **Patient video interviews.** Some developers choose to deliver multimedia patient stories while others do not. In Internet trade publications, there are anecdotal reports from Web developers about how multimedia narratives help people relate to the content [5]. In the academic setting, the Institute for New Media Studies at the University of Minnesota is developing a "best practices" list of online storytelling features and methods to guide Web content developers [6]. The Institute's analysis demonstrates the variations in Web design and content delivery styles, and reminds us, "The Web must go through a maturation process; the same process all new media have undergone." A Pew Internet & American Life Project report estimates that 21% of American Internet users have high-speed connections at home — the type of connection required for best use of multimedia [7]. Nearly half of those users say the Internet has "improved the way they get health care information." And, nearly half report using some kind of multimedia content during a typical day online. But I am not aware of any current information on multimedia use by health information seekers.
2. **Online community network.** Some developers offer online social support while others do not. The popularity of discussion groups or online "communities" is reflected in the traffic figures reported by some Web sites [8]. Computer-industry trade publications reflected on the popularity of online communities among health information seekers as long as 6 years ago [9]. While general health information seekers have shown some reluctance to join online health communities, there is evidence that those in poorer health are more inclined to use these features [10]. In one randomized clinical trial, online community members reported feeling better while lowering health care costs [11].
3. **User-specific outcomes data.** Some Web sites emphasize tailored prognostic data to users while others do not. Tailored prognostic data was a key component of one of the pioneering development efforts in the field of shared decision-making and decision support more than a decade ago [12]. Yet, until recently (until introduced as a primary feature of one of the new products in this field today [13]), the offering of user-specific outcomes data has remained on the sidelines of Internet decision-support tool development.
4. **Free, public access.** Some Web sites offer such tools to the general public at no cost and with no requirement that the user register while others require subscriptions, licenses, or registration. For newly-diagnosed individuals, the ability

to use the Internet for free to get immediate access to information at any time of day or night has always been an attractive feature.

Methods

I chose Web sites for review based on the following criteria:

- The site must offer consumers detailed information on health care treatment options and potential outcomes to help them in their decision-making.
- The site must offer such information for several different health care treatment decisions. Numerous Web sites address only one topic or condition but these were excluded from this review.
- The products must be developed for the Internet. Products originally developed for print and then converted with little or no change for Web use were excluded, since the features being reviewed were special features of the Internet. One noteworthy Web site that was excluded from review is that of the Ottawa Health Research Institute [14]. The site offers portable document format (PDF) files on 17 different decision topics. But, each is described as a booklet, worksheet, or workbook and was not designed primarily for delivery on the Internet. Since the decision aids posted there were adaptations from print or audiotape products, they were excluded from review.

The MEDLINE and Cochrane Library databases (Cochrane Database of Systematic Reviews) were searched. Individuals who are active in the field were contacted for information on current Internet decision-support tools.

Results

Five Web sites were analyzed:

- The Comprehensive Health Enhancement Support System (CHESS)
- Database of Individual Patient Experiences (DIPEX)
- Foundation for Informed Medical Decision Making (FIMDM) in partnership with HealthDialog, Inc
- MayoClinic.com
- NexCura, Inc

Comparison of Features in Web-based Patient Decision-making Tools

After a decade of development, there is still no Web site that offers all of the features analyzed in this paper: patient video interviews, an online community network, user-specific outcomes data, and free, public access. Table 1 presents a chart comparing the features of these Internet consumer health decision-making tools.

Table 1. Comparison of features in Internet patient decision-support tools

	Patient video inter-views	Online community network	User-specific outcomes data	Access
FIMDM*	No	No	No	Web services for subscribers only
CHESS	Yes	Yes	No	Access limited to consortium member groups
NexCura	No	No	Yes	Free access through co-branded partner site; registration required
DIPEX	Yes	No†	No	Free on the Web
MayoClinic.com	Yes	No	No‡	Free on the Web

* Currently none of FIMDM's outcomes data and patient interviews are available on the Internet.

† DIPEX is currently redesigning and evaluating the concept of an online social support network.

‡ MayoClinic.com pilot project to tailor breast cancer adjuvant therapy data is in development.

Dartmouth/FIMDM/Health Dialog Shared Decision-making Programs

In the late 1980s, a team of researchers based at Dartmouth Medical School began an experiment in communicating with newly-diagnosed individuals in new ways. Beginning with the topic of benign prostatic hyperplasia (BPH), the Dartmouth-based group began to communicate with health care consumers about the risks and benefits of alternative treatment and testing options for given conditions.

The team (which became the not-for-profit entity named the Foundation for Informed Medical Decision Making or FIMDM) adopted a rigorous development and review process for the content of these "shared decision-making programs" [12]. There were several distinguishing features. First, the programs' outlines of risks and benefits of alternative treatment options were based on outcomes research. At the core of the initial FIMDM development effort was the federally-funded Prostate Disease Patient Outcomes Research Team [15]. Second, the team chose to deliver the program content on a computer-based platform. This decision was based primarily on the researchers' interest in offering the individual the chance to learn his own chances of experiencing the various outcomes being described in the program. The user was asked to provide some personal information (age, symptom severity, and general health description) at the beginning of the viewing session. The computer then pulled the available outcomes data stored in the computer's database to provide to each user his own chances of experiencing the various risks and benefits of a surgical or nonsurgical choice. Third, the team conducted interviews and focus groups with health care consumers at an early stage of the program development process. What was learned from consumers (and from people who had faced the diagnoses in question in the past) made a direct impact on the final product being developed. Fourth, the stories of others who faced these diagnoses, made different treatment choices, and had different outcomes and experiences were videotaped and used in the final program. The developers believed that these video interviews would convey the real human experiences described by others who had "been there already" — better than text alone, or any combination of text, still photographs, and audio. A laserdisc player was part of the original platform because the computer

could easily access video clips from it and because it delivered high-quality, full-screen, full-motion video images.

Early Evidence of Impact

Two large managed care companies, in a pilot program using FIMDM's BPH program, reported that users of the program often chose a less-costly nonsurgical approach to the management of their urinary symptoms [16]. Most men had very positive reactions to the program, rating it generally clear, informative, balanced, and useful in helping them make a treatment decision [17]. These pilot studies provided FIMDM the impetus for creation of other shared decision-making programs. Studies of other programs produced by FIMDM attempted to document the impact of programs on prostate cancer screening [18], chronic low back pain [19,20], and ischemic heart disease [21].

At first, FIMDM worked with a business development partner (Sony Medical Systems) to license its programs to health care providers, health plans, and managed care companies. Consumers could only view the programs in the clinical setting if referred to them by their health care provider. FIMDM wanted to emphasize that these were shared decision-making programs, to be used by consumers and clinicians working together. Limiting access to the clinical setting helped ensure immediate follow-up with a physician or nurse to answer questions raised by the program. Nonetheless, providers struggled to integrate the programs into their clinical practice routine. The platform upon which the programs ran was functional (a computer, touch-screen monitor, laserdisc player, and printer). But, many viewed it as cumbersome, or as one observer described it, "expensive, unwieldy and difficult to access" [22]. The computer-and-laserdisc platform for these programs was abandoned in the mid-1990s. The programs were transferred to videotape, but in that transfer, the tailoring of the information to the individual was lost. The question of the value of such tailoring was never adequately studied.

FIMDM/Health Dialog today

Today, FIMDM and its business partner (Health Dialog, Inc, Boston) license to subscribers a telephonic nurse "health coach" service, multimedia decision-making modules on videotape and CD-ROM, a self-care handbook, and some related Web-based information [23]. However, none of the FIMDM/Health Dialog

decision-support content is available for free to the general public on the Internet.

Features

1. **Patient video interviews.** Multimedia patient stories are a core part of the FIMDM products, but none is currently offered online.
2. **Online community network.** An online social support network with other patients or consumers has never been part of the FIMDM product package, although a telephonic nurse "health coach" service is now available to subscribers.
3. **User-specific outcomes data.** FIMDM once offered tailored prognostic data on interactive computer and laserdisc programs but this feature is not available on the Internet at this time.
4. **Free, public access.** All FIMDM programs are now offered only through licenses to subscriber organizations. None is available free online to the general public.

CHESS

At about the same time in the late 1980s that the Dartmouth team was beginning work on its prototype computer-and-laserdisc program, a team with a somewhat similar mission was assembling programs at the University of Wisconsin in Madison. The Wisconsin project became known as Comprehensive Health Enhancement Support System or CHESS [24]. Its early programs addressed topics such as living with breast cancer, living with HIV/AIDS, adult children of alcoholics, stress management, and sexual assault. As is evident from some of the topics addressed, decision support is just one goal of the CHESS programs, and does not appear to be the primary goal. Part of the group's online mission statement is to develop "interactive health communication technologies that: . . . offer a variety of ways to access information, emotional support, and tools for decision making and health risk reduction [24]."

Community or social support

One distinguishing feature of the CHESS programs is the ability of users to exchange messages with others in online discussion groups or bulletin boards or submit "ask the expert" questions. The group has published results of its computer-based breast cancer social support network [26]. Among the support group benefits cited by women are these:

- "anonymity within the support group fostered equalized participation and allowed women to communicate in ways that would have been more difficult in a face-to-face context";
- "abundant emotional support, encouragement and informational support";
- the chance to "change their focus from a preoccupation with their own sickness to thinking of others."

CHESS changes through the years

For years, the CHESS programs suffered from some of the same access and delivery problems as the FIMDM computer-laserdisc programs. At first, CHESS used a DOS computer platform and loaned the systems to users. The platform changed from DOS to Windows and now programs are delivered on the Web —

but not to the general public. Patients or employees of 9 member-organizations of the CHESS Health Education Consortium must register and use a password to access the programs [27]. Current CHESS modules address the following topics: breast cancer, prostate cancer, smoking cessation, heart disease, asthma, menopause, dementia, and care giving.

Features

1. **Patient video interviews.** Multimedia patient stories are offered in the CHESS modules.
2. **Online community network.** CHESS is the only Web-based decision-support tool reviewed that offers a community or social support feature.
3. **User-specific outcomes data.** CHESS modules do not include tailored prognostic data.
4. **Free, public access.** All CHESS modules are now offered only to patients or employees of 9 member-organizations of the CHESS Health Education Consortium who must register to gain access. No modules are available online to the general public.

NexCura.com

In late 1999, Internet decision-support software began to be offered by a company now named NexCura, Inc [13]. The software is distributed through organizations that partner with NexCura, through so-called "co-branding" arrangements. These partners include the American Cancer Society, the American Heart Association, patient advocacy groups, payers, providers, and health care portal Web sites. The company claims to reach over 100000 registered patients with its oncology (Cancer Profiler™) topics alone. The programs require a user to provide diagnostic and test result information. The Profiler software matches that data with research studies and delivers information on treatment options and outcomes probabilities. Consumers can also see summaries of recent studies related to their condition. Treatment outcomes information is currently available for bladder, breast, colorectal, non-small cell lung, ovarian, prostate, and small cell lung cancers.

The presentation of evidence-based outcomes probabilities with this product is detailed, but requires a consumer to be comfortable with complicated presentation of material. An example of the co-branded Breast Cancer Profiler appears on the Web site of the Y-ME National Breast Cancer Organization [28]. Online registration is required.

Features

1. **Patient video interviews.** Multimedia patient stories are not offered in the NexCura tools.
2. **Online community network.** No community or social support feature is available in the NexCura tools.
3. **User-specific outcomes data.** NexCura tools emphasize the use of tailored prognostic data.
4. **Free, public access.** All NexCura tools are now offered free through co-branded partner Web sites. Registration is required.

MayoClinic.com

One of the first consumer health Web sites offering information free to all users on the World Wide Web was one produced by

the Mayo Clinic in 1995. The latest edition of that site is called MayoClinic.com, launched in late 2000. The site offers decision-support modules (called Health Decision Guides) on early-stage breast cancer [29], herniated disks [30], middle ear infections [31], anterior cruciate ligament knee injuries [32], colorectal cancer screening [33], and early-stage prostate cancer [34]. Others in development will address breast cancer adjuvant therapy, benign uterine conditions, and hormone replacement therapy. The programs are still available for free to anyone on the Web. Patients' stories about their treatment choice and their experience with those choices are delivered in text and in video (RealPlayer® plug-in required). There are also video interview segments with Mayo Clinic physicians.

The MayoClinic.com Health Decision Guides offer no community function. The site is developing its first Guide with tailored outcomes probabilities — on breast cancer adjuvant therapy — for release in late 2002.

Features

1. **Patient video interviews.** Multimedia patient stories are offered in the MayoClinic.com Health Decision Guides.
2. **Online community network.** No community or social support feature is offered in the MayoClinic.com Health Decision Guides.
3. **User-specific outcomes data.** No current MayoClinic.com Health Decision Guide offers tailored prognostic data, although one in development — on breast cancer adjuvant therapy — will offer that feature.
4. **Free, public access.** All MayoClinic.com Health Decision Guides are offered at no cost to the general public with no need to register.

DIPEX

In 2001, DIPEX (Database of Individual Patient Experience), a new Internet multimedia resource was introduced. DIPEX is a not-for-profit organization based at the Department of Primary Care in the Institute of Health Sciences at the University of Oxford. As much as the NexCura tools emphasize the tailoring of data to the user, DIPEX emphasizes access to the experience of others who have faced the same decisions as the user [35]. The DIPEX Web site offers video clips, audio clips, and text transcripts of interviews with people describing their diagnoses, decisions, and experiences [36].

The site is not described as a decision-support tool. However, because it includes dozens of patient perspectives on how individual treatment decisions were made, because it includes evidence-based information, and because the patient perspectives are available free on the Web as a form of 24-hour support group, it may be an important tool for those making health care decisions.

There are more patient stories on this site than in any comparable site reviewed. (Users must have the Macromedia Flash™ and RealPlayer® plug-ins in order to use the multimedia on the site.) There are currently 4 programs on the site: on breast cancer, colorectal cancer, prostate cancer, and hypertension. Anyone can access the programs on the Web for free.

Each module has a "Forum" link, which is labeled as a place "where users can post messages, comments and exchange information with other members of the DIPEX community." However, visits to those parts of the Web site on August 6, 2002 were greeted with a message: "The DIPEX forums are currently undergoing redesign and evaluation."

Features

1. **Patient video interviews.** Multimedia patient stories are offered in the DIPEX modules — more than in any other Web site reviewed.
2. **Online community network.** DIPEX is currently redesigning and evaluating the concept of an online social support network whereby messages can be posted and information exchanged among users. That feature is not available as of August 6, 2002.
3. **User-specific outcomes data.** DIPEX modules do not offer tailored prognostic data.
4. **Free, public access.** All DIPEX modules are offered at no cost to the general public with no need to register.

Discussion

Potential for new tools

One of the more difficult decisions facing a woman with early-stage breast cancer regards adjuvant therapy — chemotherapy or hormone therapy or both — following surgical removal of the primary breast tumor. For reasons described below, women facing this decision may be prime candidates for an evaluation of a hybrid tool that uses each of the 4 key Web-enabled features reviewed in this paper. The decision is difficult because prognosis is uncertain and many women may feel there are significant trade-offs in their risk-benefit analysis. If the therapy helped all women but carried few side effects, the decision would be easier. A Web-based tool could individualize the information about the risks and benefits of adjuvant therapy. Such a tool could offer the woman the chance to hear from other women in videotaped interviews and in an online social support network. And, such a tool could be delivered free on the Web to the woman's home, where she can access the information in privacy, at her own pace, and repeatedly.

Among women with early-stage breast cancer, the chances of benefit from adjuvant therapy vary a great deal. For example, a woman with a primary tumor smaller than 1 centimeter and with no sign of spread to the lymph nodes is in a different risk category than a woman who has a 5-centimeter tumor and 10 positive lymph nodes. Yet, women in these 2 different risk categories may hear generally the same risk-benefit discussion about adjuvant therapy — in the clinical setting or in educational materials.

Developers of Web-based patient decision-support tools can use technology to improve the specificity of these messages. Sometimes women are given accurate, but very general statements about a treatment's possible benefits. Sometimes they may be given generic population-wide estimates (eg, "It is thought that adjuvant chemotherapy can provide a survival benefit at 10 years of 8-15%. This means that patients with

invasive breast cancer who undergo 3-6 months of adjuvant chemotherapy or 5 years of hormonal therapy have an increase in survival of 8-15% compared to the patients who are just treated with surgery and or surgery and radiation therapy. Adjuvant chemotherapy helps 10-15% of the people who receive the therapy." [37]). But much more specific outcomes probabilities data could be given to a woman if she provided her age, the size of her primary tumor, and information about whether any cancer had been found in her axillary lymph nodes.

Mayo Clinic researchers have developed a beta-version of an online tool to deliver such tailored outcomes probabilities [38]. The tool has been described in the medical literature but has not been released to the general public [39].

The National Institutes of Health consensus panel on adjuvant therapy for breast cancer concluded its report in this way: "Methods to support shared decision-making between patients and their physicians have been successful in trials; they need to be tailored for diverse populations and should be tested for broader dissemination." [40]

There are many development and information delivery questions to test. Using the breast cancer adjuvant therapy example, it may seem intuitive that women would want to access information tailored to their own circumstances. But, there has not been adequate research conducted on the questions of whether women want to receive such tailored outcomes data, and of what difference it makes in their decision-making if they do receive such individualized information. The Mayo authors, studying this topic, believe the breast cancer adjuvant therapy decision demands such an offering. They wrote:

If anyone questions the uncertainties that abound regarding the prognosis of a primary breast cancer patient without, or with, various systemic adjuvant therapies, all one needs to do is ask four to five oncology colleagues to estimate 10-year disease free survival probabilities for a selected patient case. This will readily illustrate the wide variations of opinion in this area. To help physicians and patients make informed decisions, annual proportional risk reduction information needs to be translated into a more intuitive language [39].

Research has shown that many women with breast cancer do not recall receiving any estimates regarding prognosis [41].

Would it change decision-making if women did receive prognostic data? Would a woman over 50 years of age with a small primary tumor and no spread to the lymph nodes still choose adjuvant therapy if she knew that she had a 90% chance of being alive in 10 years without adjuvant therapy, and a 91% chance with standard chemotherapy? Would she endure the known side effects of chemotherapy to get that incremental benefit? Such questions have not been adequately studied.

Developers of Web-based decision-support tools should analyze whether women want such tailored outcomes data — and what they do with that information if they choose to receive it. Tools could be developed that offer women the chance to choose to see their own individualized prognostic data or — as an alternative — to receive valid, but generic information. The method and style of presentation of the outcomes data is an important consideration [42].

Conclusions

Technology affords health communicators many new ways of reaching health care consumers using new media. The principal investigator of the CHES project lists the following new directions interactive health communications should take over the next few years:

- conduct and disseminate more high-quality patient needs assessments;
- conduct more outcomes research on how interactive health communications systems work;
- explore the impact of developing systems that link patients directly to their providers;
- find ways to make it easy to use the Web, including encouraging sites to offer online user training [43].

Research begun at Dartmouth more than a decade ago — to track any possible post-viewing treatment shifts and actual treatment decisions made — is important to revive and continue. Tracking of patients' actual outcomes and experiences can help complete the cycle, with such data potentially being used to help guide new users' decisions.

Inadequate research has been done on the relative value of using some of the multimedia and community features of the Web in such decision-support tools. In the breast cancer example, it could be very helpful for the newly-diagnosed woman to be able to hear and watch video interviews with women who made different decisions that were rational in their respective cases. But, multimedia downloading or Web-streaming may tax many users' computer systems. The ability to add a community function, so that women could chat privately and anonymously with other women in a social support network, has been shown to have appeal. Web developers need to weigh the advantages and disadvantages of discussion groups moderated by a health care professional versus those that are not moderated. What do people trying to make health care decisions want and expect from such Web-based tools? Is the DIPEX site's emphasis on narrative storytelling any more or less important than NexCura's emphasis on delivering clinical trial information? Not enough research has been conducted or published to answer such questions. Several limitations of this review should be noted. In the fast-changing Internet environment, it is possible that a Web site that fit our inclusion criteria was overlooked.

It is also possible that some of the research questions raised herein have actually been addressed but have not been publicized because the information is held as the confidential information of for-profit ventures. However, this review demonstrates variation in the use of Web-enabled features as Internet decision-support tools are developed. This variation raises questions about what formative and process evaluation has been done and about what is being invested in the development of new tools.

In Web development, as in medicine, the old saying applies: "To a man with a new hammer, everything looks like a nail." It is possible that users do not find all of the Web's features helpful, desirable, or necessary.

It is possible to make available to many more people decision-support tools that contain all of the ideal features of

prototypes of the past decade. Research can help ascertain user needs, what works best to address them, and how today's new media can be used most effectively. Then, perhaps, the hammer will have hit the nail on the head.

Conflicts of Interest

The author was an employee of the Foundation for Informed Medical Decision Making from 1991-1997, and of the Foundation's business partner, HealthDialog, Inc, from 1998-1999. He was editor-in-chief of the MayoClinic.com Web site from January 2000 to August 2001. He is currently a consultant to the MayoClinic.com Web site.

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Abbreviations

- BPH:** Benign Prostatic Hyperplasia
CHESS: Comprehensive Health Enhancement SupportSystem
DIPEX: Database of Individual Patient Experiences
FIMDM: Foundation for Informed Medical DecisionMaking
PDF: Portable Document Format

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Short Paper

Where Are They Now? A Case Study of Health-related Web Site Attrition

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Abstract

Background.: When considering health-related Web sites, issues of quality generally focus on Web content. Little concern has been given to attrition of Web sites or the "fleeting" nature of health information on the World Wide Web. Since Web sites may be available for an uncertain period of time, a Web page may not be a sound reference.

Objective.: To address the issue of attrition, a defined set of health-related Web sites was examined at two separate time intervals.

Methods.: To determine the degree of attrition, Web sites obtained and recorded from a previous study were revisited approximately three years later. From December 1998 to May 1999, 184 Web sites were collected from which health claims were identified. During May and June 2002, the previously recorded URL for each Web site was entered into the address field of the browser Netscape Navigator. It was documented whether the original Web site could not be found, moved to a different URL location, or the URL and site location was found unchanged from the original search. For a Web site whose URL remained unchanged, it was also noted whether the site had maintained currency, (i.e. updated) since the original posting. To ensure that inaccessibility may not be due to temporary server problems, another attempt was made to access the sites at different periods of time.

Results.: When each URL address from the original set of 184 Web sites was re-entered into the address field of the browser, 108 (59%) of the sites could not be found, 31 (17%) had moved to a new URL address, and 45 (24%) of the sites could be found from the original URLs obtained in the previous study. Of the Web sites that moved to a new URL address, 7 sites provided a link from the original URL to redirect the viewer to the new location. Of the Web sites still in existence, 17 (38%) provided update information from the original posting.

Conclusions.: It can be difficult to locate information that was previously found on the Web, and if a reference to an item is provided, there is no guarantee that viewers will be able to find the site at a later time. Enhancements in Web technologies such as the Internet Archive may improve this situation. Future research that is directed toward making sure Web site viewers know the site will be accessible at a later time will enhance the Web as a valuable medical information resource.

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KEYWORDS

World Wide Web; health-related Web sites; attrition; Internet Archive; Web site quality

Introduction

"We've all heard that a million monkeys banging on a million typewriters will eventually reproduce the entire works of Shakespeare. Now, thanks to the Internet, we know this is not true" [1]. [Robert Wilensky]

The results of a recent major national survey found that about 110 million people in the U.S. — over half of the adult population — may be seeking health information online [2]. This compares with 54 million in 1998, 69 million in 1999 and 97 million in 2001. And according to the American Medical Association, on any given day, more people go online for medical advice than actually visit health professionals [3].

When considering health-related Web sites, issues of quality generally focus on Web content: how to find relevant information, and how to assess the credibility of the publisher as well as the accuracy and reliability of a document retrieved [4]. Little concern has been given to attrition of Web sites or the "fleeting" nature of health information on the Web.

Scientist and scholar Sir Isaac Newton once said, "If I have seen farther than others, it is because I was standing on the shoulders of giants" [5]. Much, if not all, scholarship is based on relation to previous work, and when new scholarly work is produced, it is important that detailed and accurate information on sources consulted are cited. To facilitate referencing, scholarly works have been routinely collected and preserved in print by libraries and database producers [6,7]. But in terms of cataloging, storage and retrieval as it relates to the Web, the status quo does not apply. With the advent of the Web, libraries must now consider Web site information that may be created, change, move, expire and disappear; with no record of the information being preserved. Few libraries made the practice of collecting copies of Web pages [8].

Since Web sites may be available for an uncertain period of time, a Web page may not be a sound reference. If a Web page or link disappears, chances are almost nonexistent of locating the reference at a later time. As a safeguard, it has been recommended that individuals keep a personal copy of Web pages as evidence that the information existed [9].

To address the issue of attrition, a defined set of health-related Web sites was examined at two separate time intervals.

Methods

In an earlier study, a systematic survey was conducted to determine the validity of health claims on the World Wide Web for the herbal remedy *Opuntia* [10]. From December 1998 to May 1999, 184 Web sites were collected from which health

claims were identified. Web sites were retrieved utilizing multiple search engines, and the Uniform Resource Locator (URL) for each Web site was recorded.

In this study, to determine the degree of attrition, each of the 184 Web sites obtained and recorded from the previous study were revisited at a later period of time. During May 2002, the previously recorded URL for each Web site was entered into the address field of the browser Netscape Navigator (version 4.7, Netscape Communication Corporation, Mountain View, California.) It was documented whether the original Web site could not be found, moved to a different URL location, or the URL and site location was found unchanged from the original search. For A Web site whose URL remained unchanged, it was also noted whether the Web site had maintained currency, (i.e. updated) since the original posting.

Since it is conceivable that inaccessibility of Web sites may be due to temporary server problems, another attempt was made to access the sites at different periods of time. For each "HTTP Error 404" or similar message obtained from the initial URL checks, an attempt to access these sites was made during June 2002 on various days and times of day in the manner described above.

Results

Results indicate that when each URL address from the original set of 184 Web sites was re-entered into the address field of the browser, 108 (59%) of the sites could not be found, 31 (17%) had moved to a new URL address, and 45 (24%) of the sites could be found from the original URLs obtained in the previous study. Of the Web sites that moved to a new URL address, only 7 sites provided a link from the original URL to redirect the viewer to the new location. Of the Web sites still in existence, 17 (38%) provided update information from the original posting. The information is summarized in Table 1.

Table 1. Attrition of Health-related Web Sites for a Three-year Period **

Web Site Sponsor (No. of Sites)	Not Found	Moved To New URL	URL Redirected	URL to Site as Original	Maintenance Update Provided
Herbal Vendor (74)	46	14	1	14	7
Food/Recipes Products (7)	5	1	0	1	0
Educational Institution(24)	12	1	0	11	6
Government Institution (3)	1	2	1	0	1
Historical Essay (8)	1	1	1	6	0
Travel and Tourism (5)	1	2	0	2	1
Message Board (15)	15	0	0	0	0
Reference Guide (16)	8	6	3	2	1
Print Media* (24)	17	2	1	5	1
Expert (7)	2	2	0	3	0
Doomsday Group (1)	0	0	0	1	0
Totals (184)	108 (59%)	31(17%)	7(4%)	45 (24%)	17 (38%)

* Includes book excerpts, newspaper and magazine articles, newsletters, a calendar reprint and a radio broadcast transcript

** Original Web site addresses and content are available on the World Wide Web at <http://ismo.ama.ttuhsu.edu/users/~veronin/WebOpuntia.pdf>

In this study, attrition is defined as the unavailability of a Web site when known to be previously accessible based on a known URL address. This did not include sites that were redirected to a new URL.

Approximately three years after initial posting, over two-thirds of the health-related Web sites reviewed could not be found or had moved with no forwarding URL, and about one-third of the remaining sites maintained currency of information. It appears that links are terminated as Web sites are moved or removed, or as servers close down. This supports the notion that it is difficult, if not impossible, to locate information that was previously found on the Web, and if a reference to an item is provided, there is no guarantee that viewers will be able to find the site at a later date.

In this study, a comprehensive data set of Web sites on a specific health-related topic was obtained, and attrition was examined. Obviously an example from a single health-related topic is limited in what conclusions should be drawn. These findings cannot be generalized to other medical topics. But this raises the question that other health-related sites on the World Wide Web may vary in their degree of attrition, and warrants further research into methods of dealing with attrition with other medical topics.

Discussion

The average life of a Web page is about 77 days [11]. The perceived value of the Web lies in the immediate accessibility to a seemingly endless pool of information with no central controlling authority. This also makes the Web difficult to maintain. According to Chris Sherman, Associate Editor of SearchEngineWatch.com, (<http://searchenginewatch.com>), as automatic maintenance, most search engines remove missing URLs from their index when they recrawl and find that the pages are gone [12]. A different problem arises, though, when an organization has gone out of business but its site still exists. This is a much more difficult problem to handle, and to date, no search engine exists to locate or remove these sites.

Enhancements in Web technologies hope to improve the problem of attrition. A prime example is the Internet Archive.

The Internet Archive

The Internet Archive (<http://www.archive.org>) is a digital library of Web pages created with the lofty goal of cataloging all of the past and present publicly available material on the World Wide Web [11]. Accessible to the public for free, it contains more than 100 terabytes of data and is growing by 10 to 12 terabytes a month. Since 1996, the Internet Archive has been storing Web pages, including graphics files, from publicly accessible Web sites. A feature implemented October 2001 known as the "Wayback Machine" allows users to go back and view earlier versions of current Web sites or of Web sites that no longer exist.

The Wayback Machine serves as a source to find Web pages when the page or host cannot be located [11]. When a user

encounters a "File Not Found" or similar message on the Web, the Wayback Machine can be accessed to find a facsimile of the Web page.

Though a significant accomplishment towards recovering lost Web pages, the Wayback Machine has limitations. It is not searchable by keywords or text in the manner of a general search engine. The user must know the precise URL of a particular Web page or site to access the Archive. Having entered a URL address, the viewer is presented with a list of dates that designates when a particular page was archived. Also, though the Internet Archive contains more than 100 terabytes of data, much is still missing. For example, it does not contain the older gopher content and other non-Web files prior to 1996, and a relatively small number of pages exists from 1996, with content increasing to recent times.

Issues of Quality and Content

The question may arise as to whether a relationship exists between Web site quality and attrition. Are poor quality sites more likely to disappear in time than sites of higher quality?

A consensus has yet to be reached as to the properties a Web site needs to have to be considered "high quality." Wilson states that "quality remains an inherently subjective assessment, which depends on the type of information needed, the type of information searched for, and the particular qualities and prejudices of the consumer" [13]. Yet many organizations and individuals have identified standards of quality that should be applied to the Web [14]. A practical approach for assessment has been described by Risk that provides benchmarks of quality [15]. It includes assessing a site for information that is accurate, current, has a clear source, is referenced, has disclaimers and cautions if appropriate, clear, clean and pleasing design features and a well-defined purpose. These criteria were applied to the original sites in this study by this author to examine whether attrition may be influenced by quality. If a site possessed at least 5 of these attributes, it was considered "high" quality, 3 to 4 attributes, it was considered "moderate," and 2 or less it was considered "poor" quality. The results are summarized in [Table 2](#).

It appears that although the high quality sites make up only a small portion of the total number of sites retrieved (15%), half of the original high quality sites (14 of 28) could be located from the original URL or were redirected to a new URL. Conversely, only 10 of the 73 poor quality sites were accessible from the original URL entry, and only one poor quality site was redirected to another URL from the original site. This suggests that Web sites of higher quality may be less subject to attrition than those of poorer quality, and warrants further research on the relationship between Web site quality and attrition with other medical topics.

Considering subject matter and attrition, it may be that certain topics (such as herbal remedies) can have periods of enthusiasm by the public then wane — which may be the case with these sites. Perhaps information on more mainstream topics (such as health risks and smoking) is less vulnerable to attrition.

Table 2. Quality of Health-related Web Sites and Attrition

Web Site Quality* (No. of Sites)	Not Found	Moved To New URL	URL Redirected	URL to Site as Original
High (28)	10	7	3	11
Moderate (83)	38	21	3	24
Poor (73)	60	3	1	10
Totals (184)	108 (59%)	31 (17%)	7(4%)	45 (24%)

* Quality assessed by author based on attributes described by Risk [15]: High = 5 or more, Moderate = 3 to 4, Poor = 2 or less

Future Considerations

It has yet to be determined with certainty the forces that influence the survival of Web sites. With the complex and dynamic nature of information flow on the Web, is there a form of "natural selection" at work in health Web site survival? If attrition is not related to the site's quality or subject matter, perhaps those with strong commercial backing may survive with greatest frequency. At this point we can only speculate what will endure.

In some instances, Web site attrition may be desirable. A common complaint against search engines is that they return too many pages, and that many of the pages have low relevance to the query [16]. The most efficient search engines index only

a fraction of the total number of documents on the Web, [17] and if sites of poorer quality go away, ideally this should help retrieval of documents of higher relevance to the user.

Most quality issues with the Web focus on consumers, [18] however, a recent major poll revealed that physicians are using the Internet to increase their medical knowledge and improve the care they provide to patients [19]. Medical information can change rapidly with continuing breakthroughs and advances in medical knowledge. Availability of information through the Web would facilitate access to the most up-to-date information on current medical topics and scientific discoveries. Future research that is directed toward making sure Web site viewers always know the site will be accessible at a later time will enhance the Web as a valuable medical information resource.

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Conflicts of Interest

None declared.

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Tutorial

Security, privacy, and confidentiality issues on the Internet

Grant Kelly; Bruce McKenzie

Abstract

We introduce the issues around protecting information about patients and related data sent via the Internet. We begin by reviewing three concepts necessary to any discussion about data security in a healthcare environment: privacy, confidentiality, and consent. We are giving some advice on how to protect local data. Authentication and privacy of e-mail via encryption is offered by Pretty Good Privacy (PGP) and Secure Multipurpose Internet Mail Extensions (S/MIME). The de facto Internet standard for encrypting Web-based information interchanges is Secure Sockets Layer (SSL), more recently known as Transport Layer Security or TLS. There is a public key infrastructure process to 'sign' a message whereby the private key of an individual can be used to 'hash' the message. This can then be verified against the sender's public key. This ensures the data's authenticity and origin without conferring privacy, and is called a 'digital signature'. The best protection against viruses is not opening e-mails from unknown sources or those containing unusual message headers.

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KEYWORDS

Access to Information; Computer Security; Confidentiality; Data Collection; Information Services; Informed consent; Internet; Organizational Policy; Privacy

Privacy

'Privacy' is a vaguely defined term that, in an online context, includes the right of an individual to:

- Determine what information is collected about them and how it is used. Sometimes we are not aware what data are being collected about us (e.g. via 'cookies' on a Web site--see Glossary) or how it may be used. Registering with a Web site (i.e. giving your name, e-mail address, medical registration number, etc.), for example, may enable that site to keep track of what you--a readily identifiable individual--view or spend online. Such information could be passed on to third parties. Some sites publish 'privacy policies' in an attempt to inform users and reduce the chances of patients or healthcare professionals placing their privacy at risk.
- Access information held about them and know that it is accurate and safe.
- Anonymity (e.g. not having your Web-browsing habits tracked).
- Send and receive e-mail messages or other data (e.g. credit card numbers) that will not be intercepted or read by persons other than the intended recipient(s). Encryption (discussed below) is one way of ensuring this.

For more information about privacy on the Internet, see [Box 1](#).

Statutory and professional considerations

Confidentiality

The ethical duty of confidentiality is defined by the British Medical Association as 'the principle of keeping secure and

secret from others, information given by or about an individual in the course of a professional relationship' [1]. In the UK the legal duty of confidentiality is underpinned by the Data Protection Act (1998), regulating the processing of information ('data') that could lead to the identification of individuals--including its collection, storage, and disclosure [2]. To ensure the protection of confidentiality in an electronic environment the General Medical Council (GMC) recommends that doctors should [3]:

- Make appropriate security arrangements for the storage and transmission of personal information.
- Obtain and record professional advice given prior to connecting to a network.
- Ensure that equipment, such as computers, is in a secure area.
- Note that Internet e-mail can be intercepted.

Consent

'Consent' for our purposes is the means by which we are authorized by an individual to process information about them based on their informed understanding of what we intend. To include identifiable patient information in an e-mail message or on a Web site in the absence of a patient's express consent would constitute a breach of confidentiality. Obtaining consent should involve making the patient aware of any risks to his or her privacy and the arrangements in place to protect it. Identifiable patient information could therefore be transmitted via the Internet with the informed consent of the patient, and with regard for the advice of the GMC (or equivalent professional body) and established principles such as those of Caldicott (see [Box 2](#)) and the Data Protection Act (see [Box 3](#)).

Textbox 1. Privacy resources on the Internet

- **Platform for Privacy Preferences Project (W3C):**
<http://www.w3.org/P3P/>
- **Understanding security and privacy (Netscape):**
- **Privacy and security fundamentals (Microsoft):**
<http://www.microsoft.com/privacy/safeinternet/>
- **e-Health Code of Ethics (Internet Healthcare Coalition):**
<http://www.ihealthcoalition.org/ethics/ehcode.html>

Textbox 2. Caldicott Principles

In relation to identifiable patient information:

- Justify the purpose(s) for using confidential information.
- Only use it when absolutely necessary.
- Use the minimum that is required.
- Access should be on a strict need-to-know basis.
- Everyone must understand their responsibilities.
- Understand and comply with the law.

For further information, see:

<http://www.doh.gov.uk/nhsexipu/confiden/report/index.htm>

Textbox 3. Data Protection Act Principles

Personal data must be:

- fairly and lawfully processed
- processed for limited purposes
- adequate, relevant, and not excessive
- accurate
- kept for no longer than necessary
- processed in accordance with the data subject's rights
- secure
- not transferred to countries without adequate protection.

For further information, see:

<http://www.hmsa.gov.uk/acts/acts1998/19980029.htm>

Information that cannot result in identification of an individual may have been 'anonymized' (where identifiers are removed) or 'aggregated' (where data from a number of individuals are summed). The requirement for consent to transmit or place such information online in this event is less certain, but perhaps prudent, although such non-personal data are not subject to legal restriction (i.e. the Data Protection Act).

Where is the enemy?

Security tends to be the progeny of scandal. A few years ago, a bank in the Midwest USA purchased a hospital along with its medical records. It coolly compared the records against its personal bank accounts, and foreclosed on the loans of all

account holders with a diagnosis of cancer. It was business-like, simple, ignorant, cruel, and an example of the damage that medical data can do in the wrong hands. Today computer 'security' is typically perceived to mean keeping hackers (those attempting unauthorized computer access) and other troublemakers from your private data. But what if such troublemakers are part of the system, or even own it?

Clearly, a simple 'cops and robbers' model does not offer enough protection, highlighting the need to ensure data security at multiple levels. The risks are internal, external, and random, and can result in data damage, falsification, loss, or leakage. It is helpful to imagine your connected system as resembling a

data stream right from your keyboard to that of the recipient, and to consider the risks along the way.

Protecting local data

Even before you connect, your data is at risk. Clearly you don't want your Internet-linked clinical system or home computer to be burnt, flooded, stolen, hit by lightning, damaged by third party software, or accessed by untrained staff or inappropriate people. You will need to back it up properly, look after the backups, and periodically reconstitute the system from backups so that you know it will work if you ever need it.

Ensure that your terminal or PC is left logged out when you are apart from it for a reasonable length of time. Most systems can be set to log out automatically by default under these circumstances and this makes good sense. Make sure that your screen shows information only to people who are entitled to see it.

If you connect to the Internet at work (e.g. via NHSnet) you may wish to ensure that your e-mail server has central control over a shared address book, with limited access rights to alter it and to reply to external addresses. Doing so prevents staff from using e-mail at work to converse with friends--which not only reduces working efficiency, but also provides a means of access for viruses (see below) and other unwelcome material.

Appropriate advice and countermeasures are detailed elsewhere [4-5], enabling you to develop robust protocols to preserve the integrity of your local system. Further NHS-specific guidance is available from the NHS Information Authority Web site: <http://www.standards.nhsia.nhs.uk/sdp/>

The risks of connecting

Open systems: the Internet

Linking computers together means that you can access other people's data, but it inevitably follows that this allows others to access data on your own system. Until such time as individual computers or networks are linked together they resemble 'islands' of electronic data. Security on a data island is simple: reassuringly firm borders trap all unauthorized entrants. However, when you build bridges by creating a network link this approach on its own is inadequate. When a computer connects to the Internet, it loses its island status by compromising the integrity of its 'borders'. Any potential benefits of connecting must be weighed against the risks to your own data. In a healthcare environment, this data is often of a highly sensitive nature. Even connecting a home computer may expose data, such as banking details, which you would prefer to remain private.

Closed systems: the intranet

Why connect in such an open way? Why not restrict the connection to 'friends' only? In other words, why don't we connect only to trusted computers over trusted network links, thus extending our own trusted computing base? Enter the intranet. Intranets are suited to smaller organizations with enforced security policies and strict personnel control--something not always attainable within a large health

service. They are by nature restrictive, as security through exclusion conflicts with the potential of a network to enhance medical communications in a connected world. Intranets may provide a false sense of security: as the electronic thief attacks the weakest link in the chain, security measures must reflect this. A properly secured intranet therefore demands such things as locked rooms for terminals, physiological checks for terminal access, and armoured, pressurized cables to detect cable tapping.

Virtual private networks

Blurring the divide between public and private networks, a virtual private network (VPN) uses a 'tunnelling protocol' and encryption (see below) to send private data through public networks such as the Internet. Although communicating parties do not need to invest in a private network infrastructure, they have no control over the network used and no guaranteed standard of service. The lack of interoperable implementations has been the main impediment to the deployment of VPNs to date [6].

Firewalls

Just as you wouldn't allow anybody to listen in to your telephone conversation, so you need to care for your Web browsing sessions and e-mail exchanges. For this purpose you need a firewall, designed to prevent damage to your system. These software or hardware devices operate by recognizing the IP address that a message or system query comes from, and only allowing past those that are recognized as 'good' or trusted. With the advent of higher-risk 'always on' Internet connections, firewall solutions of varying complexity are readily obtainable.

Protecting data in transit

Whether you are connected to NHSnet or the Internet the security threats to your data in transit are the same; data may be subject to loss, late delivery, damage, or attack. Against loss or lateness, there is little the individual can do, but damage or attack can be dealt with. You should assume the wires (or other network infrastructure) could be got at--as indeed they can--and thus must give your data a metaphorical envelope to maintain its integrity and privacy. This is precisely what cryptography can do.

Message encryption

A popular technique for protecting messages in transit is so-called asymmetric public-key infrastructure (PKI) cryptography. Alice and Bob (who wish to exchange messages) each use an algorithm based on very large prime numbers to develop two separate but related numbers, by way of typing in a pass-phrase. Both end up with an alphanumeric code that forms their 'public' key (which they publish), and an alphanumeric code that forms their 'private' key (known only to themselves and represented by their passphrase). If Alice wishes to send a message to Bob, she finds his public key (typically from a directory), writes her message, and encrypts (addresses) the data to Bob's public key, thus producing a unique set of digital data. Bob receives this in encrypted form and uses his private key to extract the data back into Alice's original text message. This process is illustrated in Figure 1.

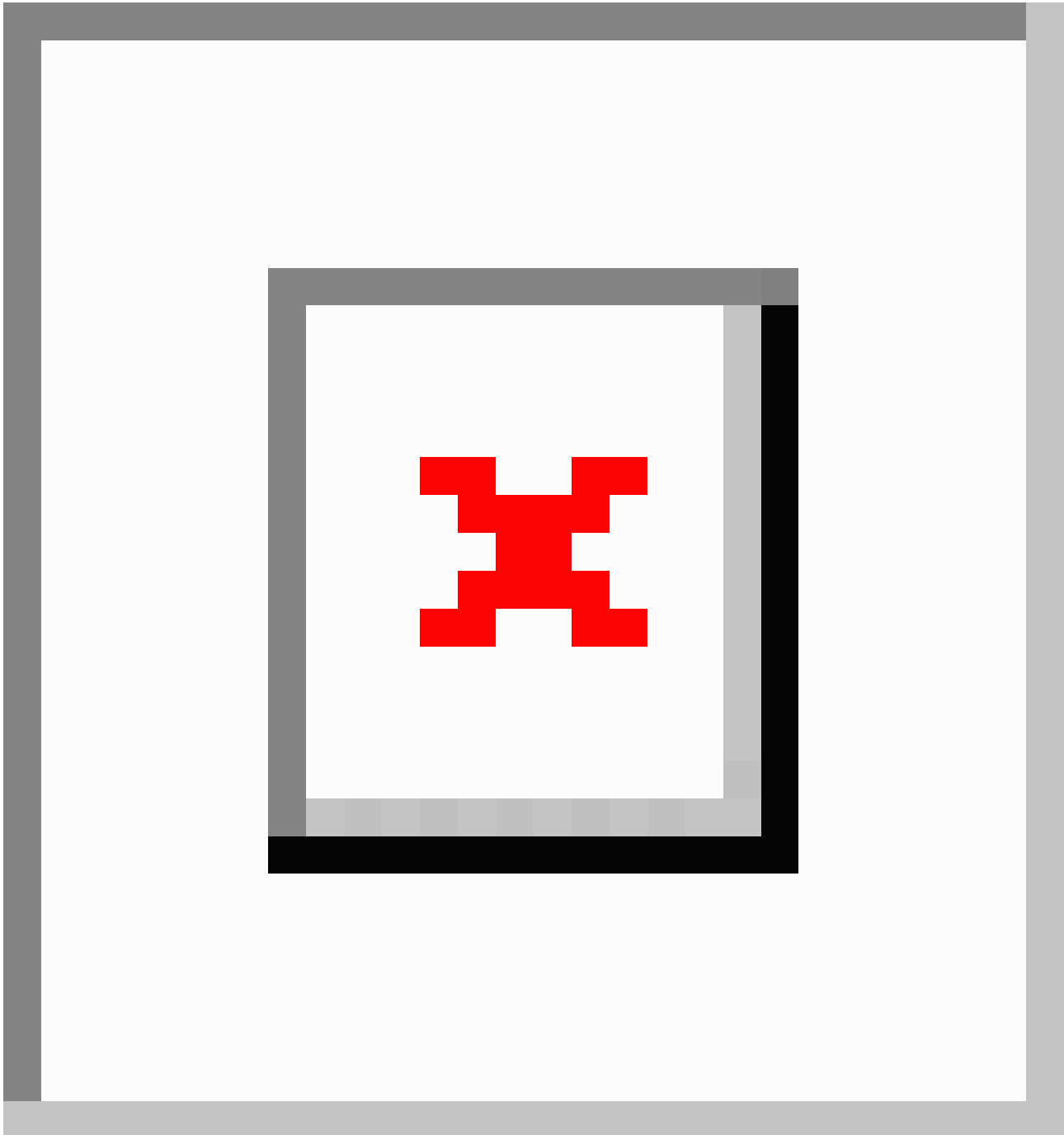
In use, this is easier than it sounds, and confers integrity (the data haven't been manipulated), authenticity (the identity of the sender is known), nonrepudiation (the data can't be disowned) and privacy on the data. Any attempt to interfere or damage the contents messes up the mathematics, and the message becomes unintelligible, thus warning the recipient not to trust it. Provided the verification of the identity of the key-holders is carried out in a dictatorial fashion, the origin authentication of the message is also assured. If only Alice knows the private phrase key to

make an exchange work, then only Alice can have sent the message.

Authentication and privacy of e-mail via encryption is offered by Pretty Good Privacy (PGP) and Secure Multipurpose Internet Mail Extensions (S/MIME), both proposed Internet standards.

- **Pretty Good Privacy (PGPi Project):**
<http://www.pgpi.org/>
- **S/MIME (RSA Security Inc.):**
<http://www.rsasecurity.com/standards/smime/>

Figure 1. Using a public/private key pair to encrypt messages helps ensure protection during transit



Browser encryption

As we move towards a browser-accessible type of electronic patient record there will arise a need to protect the exchange of

data from leakage and attack. A precedent has been set by the widespread practice of Internet banking and commerce, which out of necessity involves transmitting confidential information. The de facto Internet standard for encrypting Web-based

information interchanges is Secure Sockets Layer (SSL), more recently known as Transport Layer Security or TLS [7]. SSL/TLS can also be used to encrypt e-mail messages. It uses a symmetrical one-time electronic key that works between the browser and the server for as long as the connection is open. When the session ends, the encryption dies with it, and thus it depends largely on its length of key structure and short time of operation for its safety. SSL/TLS is more demanding on server resources than non-encrypted connections, so secured Web pages are often slow to display.

Assurance of identity (authentication) on the Web presently requires the use of a certificate supplied by a third party Certificate Authority, such as VeriSign Inc.: <http://www.verisign.com/>

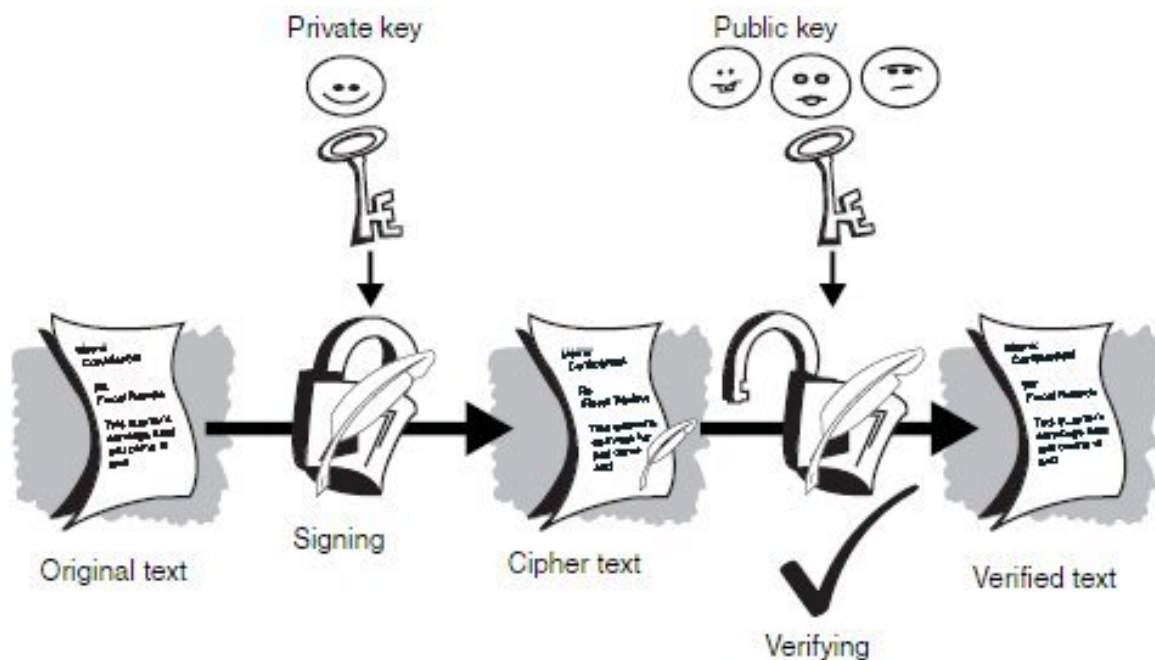
UK readers should note that the NHS has its own cryptography strategy: <http://www.doh.gov.uk/nhsexipu/strategy/crypto/index.htm>

Receiving data

Digital signatures

There is a simpler PKI process using the same algorithms referred to above to 'sign' a message whereby the private key of an individual can be used to 'hash' the message. This can then be verified against the sender's public key. This ensures the data's authenticity and origin without conferring privacy, and is called a 'digital signature'. The process is illustrated in Fig. 2. In the UK the Electronic Communications Act 2000 provides the legal framework for the recognition of digital signatures [8].

Figure 2. Using a public/private key pair to verify a digital signature



What about viruses?

Viruses are small segments of code that have been inserted into computer files, often with malicious intent. An infected file may cause annoyance or the loss of data. In theory, any file you download from the Internet is a potential vector. Viruses may also be present in files attached to e-mail messages (but cannot be transmitted via a text-only e-mail itself). There are a number of antiviral programs available (some are free) that will screen for and help you neutralize infected files on your computer--before they are activated or have a chance to 'replicate'. Some viruses are activated when you use an infected program; others merely require you to view an infected document. Antiviral programs act like the body's immune system in that they are always on the lookout for 'foreign' material--in this case, foreign

program code. However, even if your software is regularly updated it won't catch all viruses (especially new ones). Security should be based on the sound sense of not opening e-mails from unknown sources or those containing unusual message headers.

Conclusions

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

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Conflicts of Interest

None declared.

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Tutorial

Using the Internet for Surveys and Health Research

Gunther Eysenbach; Jeremy Wyatt

Abstract

This paper concerns the use of the Internet in the research process, from identifying research issues through qualitative research, through using the Web for surveys and clinical trials, to pre-publishing and publishing research results. Material published on the Internet may be a valuable resource for researchers desiring to understand people and the social and cultural contexts within which they live outside of experimental settings, with due emphasis on the interpretations, experiences, and views of 'real world' people. Reviews of information posted by consumers on the Internet may help to identify health beliefs, common topics, motives, information, and emotional needs of patients, and point to areas where research is needed. The Internet can further be used for survey research. Internet-based surveys may be conducted by means of interactive interviews or by questionnaires designed for self-completion. Electronic one-to-one interviews can be conducted via e-mail or using chat rooms. Questionnaires can be administered by e-mail (e.g. using mailing lists), by posting to newsgroups, and on the Web using fill-in forms. In "open" web-based surveys, selection bias occurs due to the non-representative nature of the Internet population, and (more importantly) through self-selection of participants, i.e. the non-representative nature of respondents, also called the 'volunteer effect'. A synopsis of important techniques and tips for implementing Web-based surveys is given. Ethical issues involved in any type of online research are discussed. Internet addresses for finding methods and protocols are provided. The Web is also being used to assist in the identification and conduction of clinical trials. For example, the web can be used by researchers doing a systematic review who are looking for unpublished trials. Finally, the web is used for two distinct types of electronic publication. Type 1 publication is unrefereed publication of protocols or work in progress (a 'post-publication' peer review process may take place), whereas Type 2 publication is peer-reviewed and will ordinarily take place in online journals.

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KEYWORDS

Clinical Trials; Confidentiality; Data Collection; Ethics, Research; Evaluation Studies; Informed Consent; Internet; Patient Selection; Qualitative Research; Research Design; Selection bias; Survey research; Research Subjects

Identifying issues for qualitative research

As the most comprehensive archive of written material representing our world and people's opinions, concerns, and desires (in industrialized countries), the Internet can be used to identify 'issues' for qualitative (descriptive) research and to generate hypotheses. Material published on the Internet may be a valuable resource for researchers desiring to understand people and the social and cultural contexts within which they live--outside of experimental settings--with due emphasis on the interpretations, experiences, and views of 'real world' people. Reviews of information posted by consumers on the Internet may help to identify health beliefs, common topics, motives, information, and emotional needs of patients, and point to areas where research is needed. Comparing recommendations found on the Web against evidence-based guidelines is one way to identify areas where there is a gap between opinion and evidence, or where there is a need for clinical innovation.

The accessibility of information for analysis and the anonymity of the Internet allow researchers to analyse text and narratives on Web sites, to use newsgroups as global focus groups, and to conduct interviews and surveys via e-mail, chat rooms, Web sites, or newsgroups. Topics suited to qualitative research include:

- Analysis of interactive communications (e.g. e-mail).
- Study of online communities (virtual self-help groups, newsgroups, mailing lists).
- Investigation of communication processes between patients and professionals.
- Study of consumer preferences, patient concerns, and information needs.
- Exploration of the 'epidemiology of health information' on the Web [1-2].

The Internet population is unrepresentative of the general population, restricting the use of the Internet for quantitative studies (i.e. studies focusing on measurement). Qualitative studies, however, do not require representative samples: 'In qualitative research we are not interested in an average view of a patient population, but want to gain an in-depth understanding of the experience of particular individuals or groups; we should therefore deliberately seek out individuals or groups who fit the bill' [3]. Three different research methodologies for qualitative research on the Internet may be distinguished:

- Passive analysis: For example, studying information on Web sites or interactions in newsgroups, mailing lists, and chat rooms--without researchers actively involving themselves.

- Active analysis: Also called participant observation; the researcher participates in the communication process, often without disclosing their identity as researcher. For example, they may ask questions in a patient discussion group implying that she or he is a fellow patient. Such studies often involve elements of deception, unless the researcher is a sufferer him- or herself.
- Interviews and surveys: See below.

Examples of these three types of qualitative research on the Internet are available elsewhere [1].

Using the Internet for surveys

Using the Internet for surveys requires an awareness of methodologies, selection bias, and technical issues.

Methodological issues

Internet-based surveys may be conducted by means of interactive interviews or by questionnaires designed for self-completion. Electronic one-to-one interviews can be conducted via e-mail or using chat rooms. Questionnaires can be administered by e-mail (e.g. using mailing lists), by posting to newsgroups, and on the Web using fill-in forms.

When e-mail is used to administer questionnaires, messages are usually sent to a selected group with a known number of participants, thus allowing calculation of the response rate. Surveys posted to newsgroups may request that the completed questionnaire is posted back to the researcher, but it is

impossible to know who and how many people read the questionnaire. If Web-based forms are used, questionnaires can be placed in a password-protected area of a Web site (i.e. participation by invitation or registration only), or alternatively they may be open to the public (i.e. any site visitor can complete the survey). The latter option makes calculation of a response rate more difficult but not impossible: the number of people who access (without necessarily completing) the questionnaire is counted and used as the denominator. Web-based surveys have the advantage that the respondent can remain anonymous (as opposed to e-mail surveys, where the e-mail address of the responder is revealed). Furthermore, they are very convenient for the researcher, as responses can be directly stored in a database where they are immediately accessible for analysis.

Electronic interviews and surveys ('e-surveys') are emerging scientific research methodologies, pioneered by communication scientists, sociologists, and psychologists, although their use for health-related research is still in its infancy [4-10]. Examples of health-related research include:

- A Web-based survey on the effects of ulcerative colitis on quality of life [11].
- Collection of clinical data from atopy patients [12].
- A Web-based survey looking at complementary and alternative medicine use by patients with inflammatory bowel disease and Internet access [13].
- A survey of dentists regarding the usefulness of the Internet in supporting patient care [14,15].

Textbox 1. Guidelines for Web-based surveys**Scenarios that may be suitable for a Web-based survey****Respondent features:**

- Respondents are already avid Internet users; e-mail addresses known for reminder messages.
- Respondents are enthusiastic form fillers; will not require monetary incentives.
- Need for respondents covering a wide geographical area (e.g. rare clinical special ties, diseases).
- Respondents are known to match non-respondents and even non-Internet users on key variables.

Survey features:

- Need for complex branching, interactive questionnaire or multimedia as part of the survey instrument.
- Survey content will evolve fast (e.g. Delphi method surveys use repeating rounds of revised questionnaires delivered over a short period, incorporating aggregate results from previous rounds until convergence is achieved).
- Intent is to document bizarre, rare phenomena whose simple occurrence is of interest.
- No need for representative results: collecting ideas vs. hypothesis testing.

Investigator features:

- Limited budget for mailing and data processing, but good in-house Web skills.
- Precautions can be taken against multiple responses by same individual, password sharing.
- Web survey forms have been piloted with representative participants and demonstrate acceptable validity and reliability with most platform, browser, and Internet access provider combinations.
- Data is required fast in a readily analysed form.

Scenarios that are unsuitable for a Web-based survey**Respondent features:**

- Target group is under-represented on Internet; e.g. the underprivileged, elderly people.
- Target group is concerned, however unreasonably, about privacy aspects.
- Target group requires substantial incentives to complete the survey.
- Need for a representative sample.

Survey features:

- Need for very accurate timing data on participants (inaccuracies in the range of seconds are added due to network transmission times, unless JavaScript or Java applets are used; see Glossary) or observational data on participants.
- An existing paper instrument has been carefully validated on target group.
- Need to capture qualitative data or observations about participants.
- Wish to reach the same group of participants in the same way months or years later.

Investigator features:

- Limited in-house Web or Java expertise but existing desktop publishing and mailing facility.

E-surveys may be part of a qualitative research process, but results can be analysed quantitatively as long as researchers are aware of potential bias (see below). In addition to gathering data, the Internet may also be used in the course of developing questionnaires, as it allows rapid prototyping and pilot testing of instruments, e.g. to evaluate the effect of framing the questions differently [16].

Several studies have checked the validity of Web-based surveys by comparing the results of studies conducted on the Web with identical studies in the real world. These seem to suggest that the validity and reliability of data obtained online are comparable to those obtained by classical methods [4,5,17-19].

However, issues of generalizability (mainly due to selection bias, discussed in detail below) remain important considerations, and the researcher should select his or her research question and interpret the results with care. The benefits and problems of Web-based surveys have been summarized by Wyatt, who suggests guidelines for when they may be appropriate (see [Box 1](#)) [20].

Selection bias

In 'open' surveys conducted via the Internet where Web users, newsgroup readers, or mailing list subscribers are invited to participate by completing a questionnaire, selection bias is a

major factor limiting the generalizability (external validity) of results. Selection bias occurs due to:

- The non-representative nature of the Internet population.
- The self-selection of participants, i.e. the non-representative nature of respondents, also called the 'volunteer effect' [21].

The non-representative nature of Internet demographics was briefly considered earlier. Considering whether the topic chosen for study is suitable for the Internet population is the first and probably the most important step in minimizing bias, thus maximizing response rates and increasing the external validity of the results [20]. For example, targeting elderly homeless alcoholics is unsuitable for an Internet survey and the results are likely to be heavily skewed by hoax responses.

Self-selection bias originates from the fact that people are more likely to respond to questionnaires if they see items which interest them, e.g. because they are affected by the items asked about, or because they are attracted by the incentives offered for participating. As people who respond almost certainly have different characteristics than those who do not, the results are likely to be biased. This kind of selection bias is more serious

than the bias arising from the non-representative nature of the population, because the researcher deals with a myriad of unknown factors and has little opportunity to interpret his or her results accordingly. Such bias may be exacerbated via loaded incentives (e.g. typical 'male' incentives such as computer equipment). Evidence suggests women are generally more interested in health topics and exhibit more active information-seeking behaviour [22], so are more likely to volunteer participation in health questionnaires. For Web surveys, the potential for self-selection bias can be estimated by measuring the response rate, expressed as the number of people completing the questionnaire divided by those who viewed it (cf. the participation rate, expressed as the number of site visitors viewing the questionnaire divided by the total number of site visitors).

Technical issues

Although a detailed analysis is beyond the scope of this chapter, a synopsis of important techniques and tips for implementing Web-based surveys provides some insight into the difficulties faced by survey designers (see [Box 2](#)).

Textbox 2. Technical issues in implementing Web-based surveys

Use of 'cookies'

Cookies can assign a unique identifier to every questionnaire viewer, useful for determining response and participation rates, and for filtering out multiple responses by the same person. As cookies may be regarded with suspicion, we recommend that researchers openly state that cookies will be sent (and the reasons for this); set the cookie to expire on the day that data collection ceases; and publish a privacy policy.

Measuring response time

The time needed to complete a questionnaire can be readily calculated by subtracting the time a form was called up by the browser from the time it was submitted using an automatic time-stamp. The response time may be used to exclude respondents who fill in the questionnaire too quickly: this may identify hoax responses, where respondents don't read the questions.

Avoiding missing data

Forms can be configured to automatically reject incomplete questionnaires and point out missing or contradictory items. Checks can be made on the client (p. 9) prior to submission, or following submission to the server (where incomplete responses can also be analysed, e.g. during a questionnaire pilot).

Maximizing response rate

The number of contacts, personalized contacts, and contact with participants before the actual survey are the factors most associated with higher response rates in Web surveys [23]. Incentives increase the risk of selection bias (see text), but less so if cash is offered. Perhaps the best incentive (and the easiest to deliver via the Internet) is the promise of survey results or personalized answers (e.g. a score). The option to complete questionnaires anonymously avoids wariness associated with requests for personal information (e.g. an e-mail address), but increases the risk of hoax responses. Researchers should be open about who is behind the study, what the aim is, and provide opportunities for feedback. Although postal surveys are superior to e-mail surveys with regard to response rate, online surveys are much cheaper [24,25]. Schleyer [15] estimated that the cost of their Web-based survey was 38 percent less than that of an equivalent mail survey and presented a general formula for calculating break-even points between electronic and hard-copy surveys. Jones gave figures of 92 p per reply for postal surveys, 35 p for e-mail, and 41 p for the Web [24].

Randomizing items

Scripting languages may be used to build dynamic questionnaires (as opposed to static forms) that look different for certain user groups or which randomize certain aspects of the questionnaire (e.g. the order of the items). This can be useful to exclude possible systematic influences of the order of the items upon responses.

Ethical issues

The ethical issues involved in any type of online research should not be forgotten [1,26-31]. These include informed consent as a basic ethical tenet of scientific research on human populations [32], protection of privacy, and avoiding psychological harm.

In qualitative research on the Web, informed consent is required when:

- Data are collected from research participants through any form of communication, interaction, or intervention.
- Behaviour of research participants occurs in a private context where an individual can reasonably expect that no observation or reporting is taking place, except when researchers do research 'in public places or use publicly available information about individuals (e.g. naturalistic

observations in public places, analysis of public records, or archival research' [33].

The question therefore arises of whether researchers analysing newsgroup postings enter a 'public place', or whether the space they invade is perceived as private. In the context of research, the expectation of the individual (whether he/she can reasonably expect that no observation is taking place) is crucial. Different Internet services have different levels of perceived privacy (in decreasing order of privacy: private e-mail; chat rooms; mailing lists; newsgroups; Web sites). The perceived level of privacy is a function of the number of participants, but also depends on other factors such as group norms established by the community to be studied. For example, in a controversial paper, Finn studied a virtual self-support group where the moderator was actively discouraging interested professionals who were not sexual abuse survivors from joining the group [34]. In those cases, obtaining informed consent (or seeking an ethical waiver, if the research could not practicably be carried out were informed consent to be required) is mandatory.

In practice, obtaining informed consent, especially for passive research methods, is difficult, as researchers usually cannot post an announcement to a mailing list or newsgroup saying that it will be monitored and analysed for the next few months, as this may greatly influence or even spoil the results, and because the mere posting of such a request may disrupt the community, and therefore be considered unethical. Researchers should therefore first obtain consent from a group moderator in order to explore whether even a request for permission is felt to be disruptive to the group process. If the moderator or person responsible for the list has no objections, one may then post a message to a newsgroup or mailing list explaining the purpose of the research, explaining that one will observe the community, assuring all participants of anonymity, and giving them the opportunity to withdraw from the newsgroup or mailing list or to exclude themselves from the study by writing to the researcher. The fundamental problem is that this may influence the communication process and may even destroy the community. Besides, participants who later join the group need to get the same information. An alternative would be to analyse the communication retrospectively and to write individual e-mails to all participants whose comments were to be analysed or quoted, asking for permission to use them; this technique has been used by Sharf [35].

In any case, researchers should make themselves familiar with the virtual community they are approaching; i.e. read the messages in a newsgroup for some time ('lurking'). Under no circumstances should researchers blindly spam (p. 31) or cross-post requests for research participation to various newsgroups.

Informed consent may also play a role when researchers report aggregate (collated and hence anonymous) data on usage patterns, such as a log-file analysis (reporting data on what Web sites have been accessed by a population). Crucial here is an appropriate privacy statement stating that these data may be analysed and reported in aggregate [28]. Note that aggregate data are exempt from the registration requirements of the UK's Data Protection Act of 1998.

In conducting surveys researchers may obtain informed consent by declaring the purpose of the study; disclosing which institutions are behind the study; explaining how privacy will be assured; and detailing with whom data will be shared and how it will be reported, before participants complete the questionnaire.

When reporting results, it is obvious that the total anonymity of research participants needs to be maintained. Researchers have to keep in mind that, by the very process of quoting the exact words of a newsgroup or mailing list participant, the confidentiality of the participant may already be broken as Internet search engines may be able to retrieve the original message, including the e-mail address of the sender. It is essential, therefore, to ask participants whether they agree to be quoted whenever there may be a retrievable archive, pointing out the risk that they may be identifiable. Problems can also potentially arise from just citing the name of the community (e.g. of a newsgroup), which may damage the community being studied.

Finding methods, protocols, and instruments

For laboratory 'bench work', researchers often need a protocol for a specific assay method. In addition to the possibility of searching literature databases, there are also specialized services on the Web that can assist in this research, such as MethodsFinder and the 'Technical tips online' database at BioMedNet:

- **MethodsFinder (BIOSIS):** <http://www.methodsfinder.org/>
- **BioMedNet:** <http://www.bmn.com/>

Sometimes asking a specific question on the right newsgroup or mailing list is also very effective. Clinical researchers may be more interested in instruments to measure patient outcomes. An excellent guide to selecting quality-of-life instruments is the Quality of Life Instruments Database at the Mapi Research Institute: <http://www.qolid.org/>

Online statistical analysis tools are available at the Simple Interactive Statistical Analysis (SISA) Web site, while background information is available within the online book Statistics at square one:

- **SISA (Daan Uitenbroek):** <http://home.clara.net/sisa/>
- **Statistics at square one (British Medical Journal Publishing Group):** <http://www.bmj.com/collections/statsbk/>

Protocols of clinical trials, which may be useful for researchers developing their own protocols, can be found in some of the clinical trial databases available on the Web, as described below.

Clinical trials and the Web

The Web is being used to assist in the identification and conduction of clinical trials.

Identifying trials

To prevent unintended duplication of clinical research, detect underreporting of research, and ease the work of systemic reviewing, it has been suggested that we should prospectively register clinical trials [36-39]. It is, however, unlikely that there will ever be one complete centralized multinational database. Instead, multiple resources set up by numerous different organizations will exist [40]. Internet technology will play a central role in linking these databases and making this information available to researchers and patients. Some scenarios in which a search of trial databases may be useful:

- A researcher wants to conduct a randomized controlled trial and wants to know whether anyone else is already running one on the same topic.
- A physician has a patient who is asking about available trials.
- A patient is looking for ongoing trials.
- A researcher is looking for possible participants for his trial.
- A researcher doing a systematic review is looking for unpublished trials.

Information about ongoing and completed clinical trials is increasingly being published on the Internet, and searches on the Web may be a useful means of complementing traditional bibliographic searches if authors of systematic reviews wish to find ongoing or unpublished trials [41].

Researchers use their personal or department home pages to announce their interest in a certain research area or to recruit patients [42]. Journals like The Lancet have begun to publish research protocols on their Web site [43], and more and more researchers will also publish 'pre-prints' (p. 239) of their findings on the Web [44].

Consumers and patient organizations also have an interest in disseminating information about ongoing trials; e.g. the National Alliance of Breast Cancer Organizations: <http://www.nabco.org/>

Government and funding agencies react to this need by establishing trial databases for consumers; e.g. the US National Institutes of Health searchable database [45]: <http://ClinicalTrials.gov>

Commercial enterprises also help researchers to recruit patients, or help patients to find clinical trials. For example:

- **CenterWatch Clinical Trials Listing Service (CenterWatch, Inc.):** <http://www.centerwatch.com/>
- **ClinicalTrialFinder.com (Clinical Data Technologies Ltd):** <http://www.clinicaltrialfinder.com/>
- **Current Controlled Trials (BioMed Central):** <http://www.controlled-trials.com>

Pharmaceutical companies and industry associations have likewise begun to recognize that openness and access to information on clinical trials and new drug developments can improve patient care and are part of social responsibility [46]. For example:

- **Clinical Trials Register (GlaxoSmithKline):** <http://ctr.glaxowellcome.co.uk/>

- **Search for Cures (Pharmaceutical Research and Manufacturers of America):** <http://www.pfma.org/searchcures/>

Finally, information or databases on ongoing clinical trials can often also be found on disease-specific sites. For example:

- **Canadian HIV Trials Network:** <http://www.hivnet.ubc.ca/ctn.html>
- **CancerNet (National Cancer Institute):** <http://cancernet.nci.nih.gov/>

Conducting trials on the Web

The Web is increasingly being used in the course of conducting large-scale multi-centre clinical trials (e.g. for remote randomization and data entry), and in the distribution of information on trial progress or protocols [47,48]. Trial centres may enter patient data using Java applets (see Glossary) that encrypt data and send it to the data centre via the Internet [49-52], where the data are stored and randomized, returning for example a study number and randomization information.

Pre-publishing and publishing research

Traditional publication is a well-defined event, whereas 'publication' in the electronic age is much more of a continuum [53], reflecting and occurring during the entire research process from hypothesis formulation to data gathering, interpretation, and the presentation and discussion of the final results. In order to distinguish online collaborative 'work in progress' from 'final' peer-reviewed publication we may term the former 'Type 1' and the latter 'Type 2' electronic publication [54]. Here, peer review is not the distinguishing characteristic: in Type 1 publication a 'post-publication' peer review process takes place. Type 2 publication will ordinarily take place in online journals. The following scenarios illustrate how researchers might use Type 1 electronic publication on the Internet:

- Sending and discussing preliminary results on mailing lists.
- Publishing drafts of scientific papers on pre-print/e-print sites (p. 239) in order to solicit comments and to improve the manuscript.
- Publishing data and information in databases; e.g. nucleotide sequences in the EMBL/Genbank databases.
- Publishing clinical trial protocols and raw data in a 'trial bank' [55].

Current awareness services

Electronic editions of paper journals and 'stand alone' e-journals typically offer subscriptions to 'TOC alerts', where users receive a table of contents by e-mail as soon as a new issue appears. The more sophisticated systems allow users to specify their interests using a controlled vocabulary, enabling the system to screen each newly published article for certain keywords or citations. Examples of current awareness services include:

- **Customised @lerts (British Medical Journal):** <http://bmj.com/cgi/customalert/>
- **JournAlert (Doctors.net.uk):** <http://www.doctors.net.uk/>
- **Journal Watch (Massachusetts Medical Society):** <http://www.jwatch.org/>

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Conflicts of Interest

None declared.

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