

***Providing Quality Preventive Health Information on the Internet:  
Consumers' Perspectives***

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## **ABSTRACT**

Objective: To explore how best to make high quality preventive health information available to consumers on the Internet in usable formats.

Design: Qualitative focus groups.

Method, Setting & Participants: Four focus groups were conducted - three at urban workplaces and one at a local hospital with patients from a rural family medical practice. There were a total of 39 participants (22 male, 17 female).

Main Findings: Five themes characterized the participants' perceptions of a consumer website of evidence-based preventive guidelines: content expectations; website design, trust, marketing, and implications of consumer health information on the Internet.

Conclusion: Consumers want information about prevention both for self-care and to participate in a more informed way in their health care when they see their physician. The findings reveal a number of ways in which consumers' use of Internet health information can impact the work of physicians and other health professionals.

Keywords: Internet; Consumer Information; Prevention; Patient Education; Focus Groups

## **BIOGRAPHICAL NOTES**

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## INTRODUCTION

The Internet is a fast developing communication tool. The number of Internet users in North America has risen from 58 million in 1997 to 100+ million in 2000 <1>. An estimated 43% of Internet users go online to gather health care data and obtain answers on health care issues <2> on over 34,000 health related websites <3>.

The Internet has moved beyond distributing static text-based information and become a communication medium that allows users to interact with information on the world wide web site. There are numerous advantages to using the Internet for consumer health information. Consumers can access information in the privacy of their own home and at convenient times. Furthermore, Internet-based health information can appeal to consumers with different learning styles <4> and combines the broad reach advantages of mass communication channels with the persuasion characteristics of interpersonal channels by allowing for give and take between the message source and receiver.<5> It has been suggested that the Internet has greater ability than other mass media to apply principles of health behaviour theories.<5>

However, along with the advantages of the Internet, there are also inherent disadvantages. The potential exists for the distribution of inaccurate medical information from unqualified sources. <4,6,7> An assessment of 60 articles published on the Internet by traditional medical sources found that only 20% followed current American Academy of Pediatrics guidelines for the treatment of childhood diarrhea.<8>, and another study found that only 4 of 41 articles on the world wide web closely followed the recommendations from published guidelines for managing fever in children at home.<9> The Scientific Panel on Interactive Communication and Health suggested that misleading information may lead to inappropriate treatment or delays in seeking necessary medical care.<7> Thus the quality and accuracy of Internet health information is an

important concern that must be assessed <9-12>. In a recent Internet survey, 69% of Internet users believe the quality of information needs to improve <13>.

Using as an example the evidence based recommendations of The Canadian Task Force on Preventive Health Care\* (CTFPHC), this study explores how best to make high quality health information available to consumers on the Internet in usable formats. The findings have implications for physicians and other health care professionals in understanding how their patients are using Internet health information, and in helping us to determine ways to facilitate consumer uptake of good quality information.

## **METHODS**

This study used focus groups <14> to gather information about consumer information needs and preferences for a website on preventive clinical practice guidelines (CPGs). Four focus groups were held in the spring of 1999. We used a purposeful sampling strategy to capture a sample of health care consumers across a spectrum of occupational backgrounds. The sites chosen were three urban workplaces (2 large manufacturing companies and one large financial institution) and one rural family medicine practice. A contact person at each site recruited participants under the guidance of the research team. Eligibility criteria required participants to be between age 35 and 65, interested in participating in a focus group discussing preventive health care information on the Internet, and to have experience “surfing” the world-wide-web, (at least 2-3 times a month). Each participant received a \$40.00 gift certificate. Ethics approval was received from the University of Western Ontario Ethics Review Board.

**Focus Group Conduct and Analysis** A trained moderator conducted the focus groups. Participants were asked questions what type of information they wanted on the CTFPHC website and how they wanted that information presented. An interview guide with specific questions was developed, but the moderator was free to word and sequence questions in the most appropriate manner and to pursue areas in greater depth <15>. The moderator summarized information to allow participants to verify interpretations and offer additional comments, a process called member-checking <16>. Each focus group ranged in length from 1-1½ hours. An assistant moderator audiotaped the focus groups and took detailed field notes. Audiotapes from each focus group were transcribed verbatim.

Following each focus group, the moderator and assistant moderator discussed the focus group and prepared debriefing notes. After the fourth group, it was felt that saturation of participants' thoughts and opinions on the content and design of a preventive CPG website had been reached. Upon completion of all four groups, the moderator and two other research team members read the transcripts independently, looking for key phrases and themes, then met to discuss their independent analyses of each transcript. During these meetings, the transcripts were coded using a list of key words and themes developed from the researchers' independent analyses. The moderator completed a secondary analysis of the data, examining similarities and differences across and within the focus groups by each theme area. The entire research team, with the exception of the assistant moderator, then discussed a comprehensive written summary of the secondary analysis. This process led to clarification and agreement on the main themes. The assistant moderator assumed the role of auditor. Independent of the other research team members' analyses, the assistant moderator analyzed the debriefing notes and transcripts, and prepared a list of key messages to compare with the results of the team analysis. This process

ensured that the findings were grounded in the perceptions of the participants, and not the biases of the researchers <16>.

## **FINDINGS**

There were a total of 39 participants (22 male, 17 female) with 8 to 12 participants per group. Fifteen participants were aged 35-40 years, 13 were 41-50 years, 8 were 51-60 years, and 2 were 61-65 years old (one participant did not provide their age). One focus group was composed of all male participants. Approximately two-thirds of participants had been using the Internet for two or more years. Twenty-six had a computer with Internet access at their workplace. Thirty-six participants had a computer with Internet access at home.

Five themes characterized the participants' perceptions of a consumer website on evidence-based preventive guidelines: content expectations, website design, trust, marketing, and implications of consumer health information on the Internet.

**Content expectations** Participants' searches were often triggered by needs for information on illness and treatment issues for themselves, friends or family members. When asked about their prevention information needs, they indicated that they wanted authoritative information on how to prevent disease. Specific topics included exercise, back care, immunization, alternative therapies, precautions for foreign travel, and nutrition.

When asked directly what screening information they wanted, participants identified information and references on screening frequency, and the impact of age and family history.

Participants wanted information presented in a balanced format, with different points of view explained and uncertainties elaborated. Furthermore, they frequently recommended including a “question and answer” page with expert responses to user questions. Some participants indicated that patient stories made information understandable and left users feeling Participants also wanted links to other health information websites, with the country of origin labeled.

**Website design** Interconnected to participants’ content expectations were their suggestions on website design, including organization of information and website navigation. Participants wanted the website to follow “and strongly recommended that the information“ Participants also wanted the information organized in layers. They asked for quick access to a brief summary of the recommendations, with the option for users to . to get more detailed information. .

Participants suggested that a schedule of age-related recommendations would help them know what issues to be concerned with at different ages. Age-related messages might also be a means to capture people’s interest. . Some participants suggested that users could enter personal information such as age and family history to have the website generate personally relevant information.

Participants wanted a website that was easy to navigate. Quick access to the home page from anywhere on the site and the use of search functions and indexes organized by topic, function, and alphabetically were suggested to enhance navigation.

Visual appeal was also important. Where . participants suggested In addition, they believed graphics made the material easier to understand. . However, in two groups, participants cautioned about increased download time with excessive use of graphics.

**Trust** A major concern of participants was how to access trustworthy information on the Internet.

The source of Internet information dominated participants' discussions of trust.

Trusted organizations included consumer advocate groups, such as the Canadian Cancer Society, and well-known medical institutions, such as the Mayo Clinic. Government-sponsored sites were generally viewed as credible, but some participants questioned potential political motives. Participants tended not to trust corporate websites, most specifically those of pharmaceutical companies, or those clearly intended to advertise products.

Participants wanted health information to be current and dated. They also wanted evidence to substantiate the information given. It helped "arm" them in discussions with their physician. There was, however, a dissenting voice.

**Marketing** In all focus groups, participants spontaneously recommended marketing the website, especially in primary care offices, and other health care facilities.

Other suggestions included television, radio, magazines, and links from the websites of other credible organizations. While registering the site with Internet search engines was recommended, one participant suggested that direct advertising of the URL was most important.

**Implications of consumer health information on the Internet** Many participants provided insight into consumers' use of Internet health information for decision making. Participants want to be actively involved in decisions made about their health. They felt information would help in their decision-making. Similarly participants would use the information to better understand an area or to help them determine what questions to ask their

physician. They used the Internet as a . and brought printouts of Internet health information to their physician. Most participants saw the Internet as an information resource, such as a library or reference manual, not a replacement for the physician.

## **DISCUSSION**

This study provides important insights into consumer perspectives on how the Internet can be used to make preventive health information accessible and useful to the general public. The findings, summarized in Table 1, also reveal a number of ways in which consumers' use of Internet health information can impact the work of physicians and other health professionals. The use of the type of information provided by the CTFPHC was helpful in orienting participants to issues related to the quality, credibility and organization of information.

Consumers want information about prevention both for self-care and to participate in a more informed way in their health care. A website could facilitate self-care by providing a link to basic information to answer general questions they have about their health or their families' health. Information from the website can also be used to prepare appropriate questions for physicians, to get more detailed information following a physician visit, or to act as a "second opinion". Arguably physicians will be disadvantaged if they are not familiar with what is available on the web and what information sources their patients are using <17>.

Furthermore, the potential exists for significant impact on the doctor-patient relationship. If patients want to share the information they find with their physicians, then physicians need to develop strategies to deal with this information. Physicians have the opportunity to encourage and accept patients' desire to bring them good information, and can reinforce the importance of quality sources. Physicians can also use information from the website as the basis for patient

handouts, and can in turn refer patients to high quality evidence-based sites. Pemberton and Goldblatt <18> suggest that if physicians accept this trend towards increasing consumer use of Internet health information, an opportunity exists for the development of a doctor-patient relationship based on trust and teamwork. Alternatively, dissuading patients' use of Internet health information could damage the doctor-patient relationship and leave patients looking elsewhere for health and medical advice. <19>

The fact that participants wanted high quality information from sources they could trust underscores the potential to use these trusted information sources to enhance shared decision-making and patient participation in their own health care.<20> It also highlights the fact that physicians and other health professionals can play an active role in helping patients get the most out of their Internet searches. They can reinforce patients' concerns about quality, enhance their skills in assessing the information found <19, 21>, and direct their patients to trustworthy sites. <22> Further research into shared decision making in the role of health information, including Internet health information, will be important as the practice of medicine evolves in this area of patient-centered care and electronic information.

The development of effective strategies for communicating and disseminating high quality evidence in a form that consumers can understand and use is key. <23> It is incumbent on organizations that generate evidence-based guidelines to develop such strategies. However, continued research is required to further understand how best to communicate evidence and better understand what consumers consider acceptable evidence.

For organizations developing evidence-based consumer information for the Internet, the task does not end with the provision of quality information. Attention must also be given to presentation. Participants wanted information in understandable language with appealing design

and good organization. Layering was also important. Beyond initial access to brief summaries they also wanted the ability to access more detailed information if they choose. Constructing information in a hierarchy on a website will help users cope with large amounts of data.<24> In this way the Internet provides an excellent means of meeting users' varying information needs and a means of dealing with complex information.<25>

The transferability of these findings to other populations is limited to those similar in description to the participants in this study. Furthermore, conducting all focus groups within a two-week period limited concurrent data collection and analysis, and the opportunity to modify the data collection process. <26> However, following each focus group researchers discussed the findings and determined if questions needed to be altered. Finally, in-depth exploration of some interesting issues was limited. For example, we did not have time to explore in detail what “evidence” meant to participants. Also, there was some indication that participants had conceptualizations of "prevention" different than those of other participants, or those of health professionals. The Task Force considers "prevention" to encompass activities related both to preventing disease ("primary prevention") as well as those related to detecting disease early ("secondary prevention"). A few participants used a more strict definition, stating that screening is not prevention because disease is already present. The main goal of these participants was to obtain information on how to prevent getting disease in the first place, including some areas where no scientific evidence is available. This gap between consumers' needs and evidence-based research has been identified in the literature.<27>

Results from this study suggest that people are using the Internet as a health information source in a variety of ways. As use expands, it will become increasingly important for physicians and other health professionals to understand how their patients use Internet health

information, and to develop strategies to deal with the information patients bring them. Our findings also indicate that consumers are concerned about the quality of information on the Internet. Physicians can help their patients use the Internet appropriately by directing them to evidence-based websites and by enhancing their understanding of what makes “quality” health information.

Although many of the findings of this study may seem evident and predictable, this paper makes several important contributions. First, there is a lack of published research on the markers that indicate to users the quality and credibility of online health information (or any type of information).<28> Establishing empirically what it is people use to decide what to believe and not believe on websites is an important first step. Secondly, user-based approaches to designing health information products, whether online, in print, or for interpersonal delivery, are key.<27> This paper provides guidance to providers of health information on how to design not only the interface, but how best to organize information, and what other features (e.g. organizational reputation, examples, evidence, etc.) to highlight, and which to avoid (e.g. commercial sponsorship) to demonstrate quality. These findings also open some intriguing avenues for future research. For example, what do consumers mean when they say “evidence”, and how does this compare to professionals’ use of this concept? Similarly, how do consumers conceptualize “prevention”? Further qualitative and quantitative research will be required to answer these questions.

Finally, the Internet could have profound effects on how patients and health professionals interact. Future research is also needed to better understand the impact of Internet health information on the doctor/patient relationship and on shared decision making.

## **CONCLUSIONS**

Consumers want information about prevention both for self-care and to participate in a more informed way in their health care. These findings reveal a number of ways in which consumers' use of Internet health information can impact the work of physicians and other health professionals.

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**Table 1: Key Messages for Physicians and other Health Professionals**

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1. Physicians and other health professionals should be aware of how their patients are using Internet health information. Participants in this study used Internet health information to:
  - Find health information for themselves, friends or family members
  - Determine questions to ask their physician
  - Get a second opinion
  - Learn more about what their physician said
  - Bring to their physician
  - Help in their decision-making
  
2. Physicians and other health professionals can:
  - Reinforce their patients' concerns about the quality of information on the Internet
  - Help their patients' learn how to judge the quality of information on the Internet
  - Direct their patients' to trustworthy websites
  - Develop strategies to work with patients and the Internet information they bring to their health care visits

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