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Electronic Dissemination of Canadian Clinical Practice Guidelines to Health Care Professionals and the Public

Canada

Canadian Task Force on Preventive Health Care

Groupe d'Étude Canadien sur les Soins de Santé Préventifs

Electronic Dissemination of Canadian Clinical Practice Guidelines to Health Care Professionals and the Public

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[*] Formerly The Canadian Task Force on the Periodic Health Examination

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Executive Summary

Background: The Canadian Task Force on Preventive Health Care (CTFPHC) is mandated "to determine how the periodic health examination might enhance or protect the health of Canadians and to recommend a plan for a lifetime program of periodic health assessments for all persons living in Canada". To complement its more traditional dissemination activities, the CTFPHC has developed and recently "launched" its World Wide Web site (http://www.ctfphc.org).

Purpose of Project: The broad purpose of this project was to find out how best to use the Internet to make evidence-based preventive health care guidelines available to physicians and consumers by an Internet website. Specific goals were to:

- determine facilitators and barriers for the dissemination of evidence-based preventive clinical practice guidelines (CPG) to Canadian health care professionals on the World Wide Web;
- determine issues related to the public's needs for evidence-based preventive health care information on the World Wide Web;
- develop an online evaluation tool to evaluate the website;
- develop a process for converting CPGs into consumer versions, including a sample of what consumer web pages would look like.

Methods: Focus groups were held with physicians and consumers to examine their information needs and to determine how we can make CTFPHC information available, convenient and usable. Key-informant interviews were conducted with consumer advocates and a public health professional to gain their insights into producing consumer health information. As a supplement, individuals from organizations involved in producing evidence-based consumer health information in the United States and Great Britain were also interviewed.

Results:

Physician Focus Groups: A common theme to all physician focus groups were the barriers that time and technology posed to accessing information from the Internet. Physician participants felt a good index system would be the easiest way to find the answer to their specific questions to help them search for information by disease, organ system or screening test. If they were looking for patient-specific information they would search based on age, gender and family history. Physicians wanted simple design with text-based information and minimal graphics. They wanted quick access to the summary of the recommendations with internal hypertext links to more detailed information, including the date and grade of recommendation. Participants also wanted links to external web sites and information that they could print and give to their patients. They also recommended strategies for increasing physician use of the site.

Consumer Focus Groups: Consumers wanted to know what they could personally do to prevent disease as well as what their doctor could do. They gave a number of suggestions for the content and design of a consumer web site. Other discussion points included issues of trust on the Internet, marketing our web site, and how they used health information from the Internet.

Consumers wanted a site that included information they could understand in lay language. It was important to include evidence to support the recommendations made. When evidence was unclear, they wanted the facts clearly stated so that they could come to their own decision. Some participants suggested that hearing about other people's experiences would be extremely helpful. Participants wanted a site that could be navigated easily by novice computer users, including access by an index system, search features, and an alphabetical list of topics. Graphics, colour, and text should capture their interest. Participants also recommended linking to other web sites. Participants strongly advocated marketing the CTFPHC web site in physician offices and health care facilities, and via the mass media. These consumers often printed health information from the Internet to take to their physician. Internet information also helped them to become more informed and know what questions they should ask their doctor.

Key-Informant Interviews: We discussed with key informants the process of developing patient information materials, with a focus on how they obtained input from consumers. They reported gathering this input at different stages in the process, both before the materials were developed, in order to understand what the consumer/patient issues and information needs were, and to later test the materials. Preparing targeted print information was a challenge for all organizations, and each had developed different strategies to meet this challenge. The key-informants felt the Internet would play a significant role in the dissemination of consumer health information in the future, although there was debate over what should be included on the Internet (print materials or interactive materials) and if there should be additional ways of disseminating information to the public. All organizations were interested in the information produced by the CTFPHC.

Organizational Interviews: All organizations interviewed had been involved in developing consumer health information from evidence-based reports. The main impetus for this was to have informed consumers. All interviewees reported that the development of consumer information materials was a highly iterative, complex and lengthy process requiring multiple drafts and feedback mechanisms from a variety of experts and consumers. Consultations with consumers were a central part of the development process.

Discussion: This project has given the CTFPHC many insights into the enhancement of our physician web site and a number of issues to consider for the development of a consumer area for the site. It is apparent that the Task Force has a large body of useful and credible information. High quality information is the most expensive component of developing a quality web site. Many of the design and format suggestions from the physician focus groups can be incorporated into the current CTFPHC web site. This will create a site that can provide quick and easy access to information so physicians can get the answers they need. Developing consumer health information in simple and understandable forms, however, would represent a significant initiative for the CTFPHC. Based on the findings from the focus groups and interviews, consumers want basic health information written in understandable language. There would also be challenges in balancing consumer information needs with the available research evidence. Prior to developing these consumer health information materials, some basic decisions will need to be made about the (1) intended aims; (2) proposed audience; and (3) the intended context of use of this information. The current research provides a strong foundation for further development and exploration of these issues.

Background

The Canadian Task Force on Preventive Health Care (CTFPHC) is an independent scientific panel comprised of university-based clinician-methodologists from diverse clinical backgrounds. It was established in September 1976 by the Conference of Deputy Ministers of Health of the ten Canadian provinces. Its mandate was and is "to determine how the periodic health examination might enhance or protect the health of Canadians and to recommend a plan for a lifetime program of periodic health assessments for all persons living in Canada". [1]

The Task Force spent the first several years of its existence evolving and refining a standardized methodology for conducting systematic reviews of the available research evidence. This included developing a “methodological hierarchy” by which different study designs could be evaluated, and a classification of recommendations to indicate whether there is evidence to include or not include given preventive actions in the periodic health examinations of asymptomatic people. When research does not provide clear guidance, this lack of evidence is articulated, leaving the decision to the clinician’s professional judgment and assessment of the individual case.

The Task Force recognizes that in clinical practice, caregivers dealing with individual patients must make binary decisions – **“do it” or “don’t do it”**. It also recognizes, however, that for many preventive interventions, the scientific evidence does not lend itself to such simple two-dimensional alternatives. The particular characteristic that distinguishes the Task Force methodology from traditional approaches to decision-making on prevention issues is that evidence takes precedence over consensus (CTFPHE, 1994).

A primary Task Force goal is to provide a bridge between research findings and clinical preventive practice. A major objective is to help clinicians choose tests, counseling strategies or other preventive interventions of proven utility and avoid those that lack demonstrated value.

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[1] The periodic health examination (PHE) is a group of activities, encompassing both primary and secondary prevention, designed either to determine a person’s risk of developing disease or to identify early, asymptomatic disease. Primary prevention aims to prevent the occurrence of disease through immunization, and counseling for lifestyle change and risk reduction. Secondary prevention aims to identify asymptomatic individuals with early stage disease when such early identification promises significantly better response to treatment than in those who first present with symptoms. Canadian Task Force on the Periodic Health Examination, 1994, p. ix

Current Project

Historically, the CTFPHC has made its recommendations available to physicians through peer-reviewed journal articles and monographs (1979, 1994). To complement its more traditional dissemination activities, the CTFPHC has developed and recently "launched" its World Wide Web site (http://www.ctfphc.org). The purpose of this project was to find out how best to use the Internet to make evidence-based preventive health care guidelines available to both physicians and members of the general public. Focus groups were held with physicians and consumers to examine what their information needs are in this area and to determine how we can make this information available in convenient and usable forms. Key-informant interviews were conducted with consumer advocates and a public health professional to gain their insights into producing consumer health information. As a supplement to this information, individuals from organizations involved in producing evidence-based consumer health information in the United States and Great Britain were also interviewed. This research will help further develop the current web site designed for clinicians and will allow the Canadian Task Force on Preventive Health Care to explore the issues involved in developing a web site with information directed to members of the general public.

The contract deliverables (synthesized across the physician and consumer initiatives), as follows, are presented in this report:

1. A bibliography (with annotations for key papers) and synthesis of the current preventive health care research literature with a focus on internet-based dissemination of preventive clinical practice guidelines for both physicians and consumers.
2. Results of 4 focus groups with family physicians, 4 focus groups with consumers, and key informant interviews with consumer advocacy groups to identify facilitators and barriers to using internet-based clinical practice guidelines.
3. Derived from #2 above, a list of principles or key issues to consider when developing WWW sites to disseminate clinical practice guidelines to Canadian clinicians and consumers.
4. A draft online questionnaire that could be used to evaluate CTF website use following a future monitored use period with a selected sample of participating family physicians.
5. A proposed plan to develop a process for converting CPGs into consumer versions, and a sample of consumer web pages for a selected topic (revised from original deliverable, with permission of scientific authority).
6. A plan outlining the dissemination of these results.

Literature Review and Synthesis

This review of the literature is presented in two sections: (1) Physician Information; and (2) Consumer Information. The first part of the review will examine issues related to the dissemination of information to physicians and the ways in which advancing computer technologies may assist in this process. The second part of the review will look at issues involved in the development of consumer health information. The report will first examine the issues of producing written consumer health information, followed by a look at the use of computers and Internet technologies in making this information more available to consumers.

An underlying premise of this research is that the provision of factual information, even at a basic level, serves as a necessary, but not sufficient, component of a process that may or may not lead to behaviour change. Information seekers come to look for (or accidentally run across) information for a variety of reasons, and with a variety of outcomes. Information is normally seen as that which reduces uncertainty for the seeker, and thus has meaning (Dervin, 1977; Belkin, 1978; Buckland, 1991). However, information can also increase uncertainty and create more dissonance (Rogers, 1983). The information seeking process is iterative, and depends largely on the seeker's specific situation, and broader context (Dervin 1992, 1997). These factors, along with the nature of the information sought and found, ultimately determine how the information will or will not affect behaviour change. This is a recurrent theme in the literature and theories reviewed below. Thus, it is not within the scope of this report to determine the role of information in changing or not changing a person's health-related behaviours. Instead, we propose that before any such change process can even begin, it is necessary to ensure that high quality information is made available to users, in convenient and usable formats, as a starting point to an ongoing process involving looking for and integrating new information to make decisions about health behaviours.

Physician Information

A recent criticism leveled at Clinical Practice Guidelines (CPGs) in general is that many are not implemented in clinical practice, and thus do not reach their goal of improving quality of health care to patients (Berger & Rosner, 1996; Haynes & Haines, 1998; Hayward, Guyatt, Moore, McKibbon & Carter, 1997). The reasons for this apparent failure are many and diverse. Strategies have been developed and tested to address the gap between the production of CPGs and their application in practice. The Canadian Task Force on Preventive Health Care (CTFPHC) recently reviewed the effectiveness of strategies and theoretical approaches to dissemination, uptake and implementation of CPGs. Continued use of the CTFPHC web site as a major dissemination channel was one of the features in the dissemination and implementation model proposed in this review (CTFPHC, 1999).

The following paragraphs will look at physician information seeking behaviours and the role that advancements in computer technology, specifically the Internet, will play in the dissemination of clinical practice guidelines to physicians.

Physician information seeking and information use behaviours

A number of the barriers to implementation of CPGs in clinical practice are related to physician information seeking and use behaviours (Hibble, Kanka, Pencheon & Pooles, 1998; Haynes & Haines, 1998). These barriers include: lack of time, information overload; lack of training in the use of information sources; inadequate information management skills and systems; and lack of training to evaluate and apply research evidence (CTFPHC, 1999)

A meta-analysis of physician information sources found that physicians have a preference to use books and journals to access needed information. Furthermore, they often consult with their colleagues for answers to clinical and research questions (Haug, 1997). Similarly, in a study of Canadian physicians to understand their information preferences, needs and uses, it was reported that informal discussions had the greatest impact on clinical decision-making. More formal training and reading were also influential. The sources reported as having the least impact on clinical decision-making were: pocket notes, clinical practice guidelines, brief updates, original research articles, position papers, computerized literature searches, and insurance plan policies (Hayward et al., 1997).

Accessibility appears to be an important factor in influencing family physicians' use of information. In a review of articles on the use of information sources by family physicians, Verhoeven, Boerma, and Meyboom-de Jong (1995) found that accessibility was more important than factors related to quality (i.e. reliability and completeness of the information). Similarly, Sackett & Straus (1998) found that when evidence-based information was made easily available to physicians in a teaching hospital, the use of the evidence increased. One of the challenges in disseminating information to physicians will be to increase the accessibility of that information.

Increasing Information Accessibility through the Internet

With the emergence of the Internet, the use of computers is increasing the accessibility of information to physicians. More and more medical resources are available on the Internet for family physicians. From e-mail, listserves and online journals, to informative web sites including continuing medical education web sites, the Internet provides access to a wide range of medical information (Anthes, Berry & Lanning, 1997).

Libraries (especially the National Library of Medicine) have made the medical literature more and more accessible, most recently by allowing free Internet-based access to the most current version of the MEDLINE database. Also, many medical journals have made themselves available online. A common feature of the better ones is an alerting service, which emails subscribers the table of contents of new issues. One of the best examples is the *British Medical Journal*, which provides this, plus many more useful services.

Evidence-based guidelines are also available on the Internet. Individual CPG producers have developed web sites to make their work available (e.g. Cochrane Collaboration, Canadian Coordinating Office for Health Technology Assessment). Compendium sites have also begun to emerge as clearinghouses for guidelines (e.g. the Canadian Medical Association's CPG Infobase, the UK National Health Service's Bandolier Evidence-Based Medicine Website, and the US Agency for Health Care Policy and Research's National Guideline Clearinghouse[2]).

In October 1998, the Canadian Task Force on Preventive Health Care implemented a web site allowing for Internet access to the Task Force’s recommendations. User-sessions on the web site have steadily increased from just over 4,000 in October 1998, to over 14,000 in May 1999. A marked increase in user-sessions was observed when the web site was officially launched by press release in March 1999, where the number of user-sessions jumped from 9,615 in February to 18,011 in March 1999. Of particular interest is the user-session length. Over the 8 months that the web site has been on-line, the average user-session length is over 10 minutes.

Despite the increasing access to information sources on the Internet, the role that the Internet will play in meeting primary care information needs remains uncertain (Westberg, Randolph & Miller, 1998). A recent Canadian Medical Association (CMA) resource

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[2] CMA Infobase: http://www.cma.ca/cpgs/index.htm; NHS Bandolier: http://www.jr2.ox.ac.uk:80/Bandolier/; AHCPR Guideline Clearinghouse: http://www.guideline.gov

questionnaire suggests that physician Internet use is increasing. Fifty percent of general practitioners/family physicians currently use the Internet, with another 37% planning to do so within a year. The most common activities of physicians on the Internet included e-mail, searching the world-wide-web, and bibliographic database searching (CMA, 1998).

Increasing Information Accessibility through Computer-based Decision Support Systems

In addition to making information more accessible to physicians via the Internet, some researchers and developers are looking at ways to use computers to assist physicians in incorporating information into the clinical decision-making process. Haynes and Haines (1998) suggested that one of the solutions to getting research evidence into clinical practice was to use information technology to integrate appropriate maneuvers into patient care. A means of doing this is by embedding CPGs into computer-based decision support systems (CDSS). In a systematic review of controlled trials, it was found that a computer-based clinical decision support system enhanced physicians' performance for preventive care (Hunt, Haynes, Hanna & Smith, 1998). Similarly, a study examining the implementation of computerized clinical practice guidelines in clinical settings found an increase in physician compliance with guidelines (Lobach & Hammond, 1997). More research is needed to determine the impact of CDSS on patient outcomes.

Systems are also being developed to present CPGs in a relational database (Lobach, Gadd, & Hales; 1997). Prototypes have been developed to convert text-based CPGs to a relational database, with the ultimate goal of providing interactive, guideline-based decision support on the Internet (Hales, Gadd, & Lobach, 1997; Liem, Obeid, Shareck, Sato & Greenes, 1995). The advantage of developing a web-based system is that there would be easy access for everyone with an Internet connection.

Summary

In order for physicians to use evidence-based information, research has shown that the information must be accessible. Provision of information to physicians on the Internet appears to be one means of increasing the accessibility of that information. Further advancements in computer technology through the use of computer-based decision support systems and relational databases may provide more sophisticated means of not only making the information more accessible, but also making it available in more applicable forms. For a discussion of ways to address some of the other barriers to provision, uptake and implementation of CPGs (to and by professionals), the reader is referred to the 1999 Canadian Task Force report on this subject (CTFPHC, 1999).

Consumer Information

This section of the literature review examines the development of consumer health information. Because most of the work has been done on print media, the report will briefly outline the development of written consumer health information. It will then follow with a look at current literature on the use of the Internet to disseminate health information to consumers.

Print Media

In general, written materials are most effective in teaching new knowledge or giving information (Frank-Stromborg & Cohen, 1991). Simple written information has been shown to increase recall of diagnosis and increase patient satisfaction (Patterson & Teale, 1997). Roland and Dixon (1989) found that an informational booklet, given to patients presenting in general practice with back pain, increased patient knowledge and had some effect on altering the behaviours of patients. In a qualitative study, patients' felt that a printed summary of information enhanced the patient-provider relationship, improved satisfaction with care, and motivated adherence to treatment (Tang & Newcomb, 1998). Most often, patients preferred the use of written materials in conjunction with other methods of instructions (Cooley, Moriarty, Berger, Selm-Orr, Coyle & Short, 1995; Foltz & Sullivan, 1996). Others have suggested that the provision of patient information can help patients make better decisions (Coulter, Entwistle & Gilbert, 1999; Entwistle, Sheldon, Sowden & Watt, 1996).

There are a number of issues to consider when developing written consumer health information. Such issues include readability, presentation and style, and the use of narratives, and health behaviour theories.

Readability

Written patient information is only useful if patients can understand the material, otherwise it is a waste of resources (Meade & Smith, 1991; Mumford, 1997). Therefore, readability of patient information materials has been a major focus in the literature. A number of studies have investigated the readability levels of health information using readability formulas including Flesch, Fry, FOG and SMOG to name a few. Studies have consistently found that the reading level of consumer health information was too high for a large portion of the adult population (for examples see: Davis, Crouch, Wills, Miller & Abdehou, 1990; Meade, Diekmann, Thornhill, 1992; Merritt, Gates & Skiba, 1993; Mumford, 1997; Vivian & Robertson, 1980).

Despite their usefulness, many authors have cautioned against relying too heavily on readability estimates. Readability estimates measure sentence length and vocabulary difficulty but they do not measure comprehension (Merritt et al., 1993; Meade & Smith, 1991). Authors have also cautioned that educational level does not indicate reading level (Foltz & Sullivan, 1996) and reading ability does not ensure comprehension (Owen, Johnson, Frost, Porter, & O'Hare, 1993). As a result, expert judgement and testing of the materials with the target population are required in addition to testing the readability formula (Merritt et al., 1993).

There does not appear to be a suggested standard reading level for consumer health information materials. For example, the National Literacy and Health Program (1999) for the Canadian Public Health Association does not suggest a specific grade level for written information. Instead, they make the following recommendations for producing "plain language" health information:

- cover only 3 to 5 points
- use simple graphics and techniques to highlight important points
- use short words and short sentences
- use common words, not technical jargon
- give practical information

As can be seen by these suggestions, developing "plain language" health information involves more than just readability.

Issues Beyond Readability: Presentation, style and more

In addition to testing the readability of materials, a number of other suggestions have been made for developing useful written materials for patients. Meade and Smith (1991) argue that in developing written information materials, it is important to consider issues such as motivation, visual attractiveness, and cultural and experiential factors. They also highlight other issues such as learnability (e.g. reading ease, assessment of the reasons why people may want to read the text) and text style (e.g. balancing of white and black space, appropriate font size, and consistent formatting) that need to be considered in the development process. Likewise, Kripalani (1995) and Baker (1991) offer a number of suggestions for creating written patient information. Suggestions include writing in the active voice and personalizing the message by writing in the second person. While there is consensus in these suggestions, there appear to be few systematic comparisons of different presentation styles in the literature. A list of suggestions for developing written consumer health information is included in Appendix 1.

Narratives

The use of narratives in clinical practice has been identified as a way to help diagnose patient problems and determine treatment options (Greenhalgh & Hurwitz, 1999). Narratives create an educational experience that is memorable and grounded in experience. The use of narratives also promotes reflection (Greenhalgh & Hurwitz, 1999). Some argue that the application of research evidence into clinical practice can be facilitated by using narratives as the vehicle to deliver research results not only to consumers, but also to clinicians, policy makers and politicians (Enkin & Jadad, 1998).

Using health behaviour and communication theories to develop health information

Health behaviour and communication theories have provided ways to think about motivating and influencing individuals and groups to adopt healthy behaviours. These theories are considered in the context of the development of consumer health information materials. First, most health behaviour and communication theories emphasize understanding consumer needs and recommend developing messages directed to a target audience. For example, the social marketing model suggests that the following issues should be addressed when developing health information materials: (1) identify and understand the needs of consumers; (2) segment consumers into target groups; (3) pretest messages with the different target groups; and (4) conduct ongoing evaluation (Farquhar, Formann, Flora & Maccoby, 1991). Similarly, the Stages of Change theory recognizes that there are different stages in the change process (Prochaska, 1991; Prochaska, DiClemente, Norcross, 1992; Prochaska, Velicer, DiClemente, Fava, 1988). Therefore, strategies used need to match the intended audience's stage in the change process. This means that different people will require different messages depending on the stage at which they are in the change process (Hyndman, Libstug, Giesbrecht, Hershfield, Rootman, 1993).

Secondly, because behaviour change is a complex process, health behaviour theories encourage the use of multiple behaviour change strategies. For example, the Social Cognitive Theory suggests that individuals' beliefs about healthy behaviours are important, and thus accurate information is a necessary component in modifying incorrect beliefs. However, in addition to simply having access to information, other strategies such as environmental changes and skill development are needed to support behaviour change (Baranowski, Perry & Parcel, 1996).

Table 1: Common health behaviour theories and models.

In a review of 24 journals in health education, medicine, and behavioural sciences published between mid 1992 and 1994, Glanz, Lewis, & Rimer (1996) identified the following theories and models as the ten most commonly referred to in the literature.

Individual-level change	Health Belief Model Self-efficacy Theory of Reasoned Action Stages of Change/Transtheoretical Model
Interpersonal-level change	Social Cognitive Theory Social Support
Community-level change	Community organization Diffusion of innovation
Models of Behaviour Change	Social Marketing PRECEDE-PROCEED model

Again, an examination of the entire behaviour change process is beyond the scope of the current research, in particular with regards to how best to incorporate these theoretical approaches when considering the development of Internet-based consumer information.

Criteria for evaluating quality of patient information

Some checklists and suggested guidelines for evaluating health information have been published (Centre for Health Information Quality, 1997; Coulter et al., 1999; Frank-Stromberg and Cohen, 1991). These checklists include content related issues such as accuracy, currency of information, and references; and process issues such as patient involvement and cost-effectiveness. However, due to the lack of evidence about impact of patient information on important outcomes, Entwistle, Watt, Davis, Dickson, Pickard and Rosser (1998) indicate that it is impossible to identify the “gold standard” of patient information materials.

Entwistle et al. (1998) argue that a number of skills are required to prepare patient information materials from research evidence to support patient decision-making. These include: (1) evaluation of research evidence; (2) identification of patients beliefs, concerns and needs; (3) understanding the context into which the information materials will be introduced; and (4) production skills including writing, designing, peer reviewing, piloting, revising and distributing materials. Based on the skills and expertise required to produce the patient information, Entwistle et al. (1998) suggest that evidence-based patient information designed to support shared decision-making should be developed at the national level. They suggest that local development may be more subject to compromises and manipulation of the research evidence. However, others suggest that local development of materials could lead to greater use of the information. Several studies of professional involvement in the uptake of clinical practice guidelines have shown that local involvement can enhance uptake and implementation (Onion et al., 1996; Conroy & Shannon, 1995; Gates, 1995). Involving local consumers could have the same effect, however this remains an area that is not well understood.

This section has outlined some important issues to consider in the development of written patient information including readability, presentation and style issues and the use of narratives, research evidence, and health behaviour theories in the development of written patient information. However, there are additional issues to address when developing patient health information for the Internet, as follows.

Consumer Health Information on the Internet

The Internet is a fast developing communication tool. It 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 (Richards, Coman, Hollingsworth, 1998). Cassel, Jackson, & Cheuvront (1998) propose that the Internet 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. They suggest that the Internet has greater ability than other mass media to apply principles of health behaviour theories.

The Science Panel on Interactive Communication and Health identified the following advantages of interactive health communication (Robinson, Patrick, Eng & Gustafson, 1998):

- improved opportunity to tailor messages;
- improved use of media to match learning styles of users;
- increased possibility for users to remain anonymous, which may increase their willingness to engage in frank discussions;
- increased access to information and support on demand;
- increased opportunity for interaction with health professionals and/or support from others;
- enhanced dissemination capabilities and opportunity to keep content current.

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 (Richards et al., 1998; Coiera, 1998; Robinson et al., 1998). In an assessment of 60 articles published on the Internet by traditional medical sources, McClung, Murray, and Heitlinger (1998) found that only 20% followed current American Academy of Pediatrics guidelines for the treatment of childhood diarrhea. Similarly, Impicciatore, Pandolfini, Casella, and Bonati (1997) 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. The Scientific Panel on Interactive Communication and Health suggested that misleading information may lead to inappropriate treatment or delays in seeking necessary medical care (Robinson et al., 1998).

A number of authors have argued that we must assess the quality of information on the Internet (Impicciatore et al., 1997; Eysenbach & Diepgen, 1998; Silberg, 1997; Wyatt, 1997). There are two broad factors impacting the quality of Internet health information: (1) content issues; and (2) barriers to the effective use of technology. Therefore, comprehensive instruments are required to assess the quality of the information.

(1) <u>Content issues</u>: In a review of published criteria for evaluating health related web sites, the most frequently cited criteria included: content (quality, reliability, accuracy, scope and depth); design and aesthetics of site, disclosure of authors, sponsors, developers, currency of information (frequency of update, maintenance of site), authority of source, ease of use, and

accessibility and availability (Kim, Eng, Deering, & Maxfield, 1999). The authors indicated that the next step is to develop a simple set of criteria that the general public can understand. However, in a similar review, Jadad and Gagliardi (1998) concluded that it was unclear "whether they [instruments to evaluate health information on the Internet] should exist in the first place, whether they measure what they claim to measure, or whether they lead to more good than harm." (p. 614) Furthermore, the authors questioned whether users would even notice evaluations of the information.

(2) <u>Barriers to the effective use of technology</u>: In addition to concerns about content quality, several authors discuss such access barriers as cost, geography, literacy, culture and disability. It is argued that the Internet may increase the gap in health information between the "haves" and "have-nots" (Eng, Maxfield, Patrick, Deering, Ratzan & Gustafson, 1998). There are also concerns about breach of privacy and confidentiality of consumers. Furthermore, readability issues are also a concern on the world-wide-web. Graber, Roller & Kaeble (1999) found that, on average, patient information from the world-wide-web was written at a 10th grade, 2nd month reading level. The authors felt that although this may be appropriate for current web users, readability will become a concern as the accessibility of the world-wide-web increases and as physicians start giving information from the world-wide-web to their patients.

Impact of Patient Information on Clinical Outcomes

A key question for organizations investing resources in web site development will be the impact of Internet health information on clinical practice and patient outcomes. Wyatt (1997) indicates that we need to see published trials on the effect of information dissemination via the World Wide Web on clinical practice before there is large-scale expenditure on web sites. Such studies are not yet published (Coeira, 1998; Wyatt, 1997).

Current Study

The purpose of this project was to identify issues and strategies that would enhance the use of the Internet to make evidence-based preventive health care guidelines available to both physicians and members of the general public. Focus groups were held with physicians and consumers to determine what their information needs are in this area and to determine how we can make this information available in convenient and usable forms. Historically, focus groups have been used in marketing research to identify consumers' needs and preferences. They are also a useful research technique for gaining insights from health care professionals and consumers on their information needs (af Klercker and Zetraesu, 1998, Coulter, Entwistle and Gilbert, 1999).

Key-informant interviews were also conducted with consumer advocates and a public health professional to gain their insights into producing consumer health information.

Methods

This study used the qualitative methodologies of focus groups and key-informant interviews to collect the data. Focus groups were held with physicians and consumers. Key-informant interviews were conducted with consumer advocates. Focus groups and key-informant interviews allow for the collection of in-depth information on people's thoughts, feelings, behaviours, opinions and beliefs (Patton, 1990). These research methods help to acquaint the researcher with the terminology used by the groups of interest.

General information about physician and consumer information needs with respect to preventive health care recommendations was gathered during the focus groups. In addition, their thoughts on how to organize this information on a web site were collected. In the key-informant interviews, consumer advocates were asked about their experiences in developing consumer health information and the relevance of the CTFPHC recommendations in their work.

The focus groups and key-informant interviews followed an interview guide approach where the interviewer is free to word and sequence questions in the most appropriate manner and to pursue areas in greater depth if desired (Patton, 1990). An interview guide was developed for the focus groups and key-informant interviews (See Appendix 2, 3, & 4)

Physician Focus Groups

Four physician focus groups were held in the month of April, 1999. A total of 34 physicians participated in these focus groups, 23 male and 11 female. Three of the four focus groups were held in a major urban centre. The fourth focus group was held in a small community hospital located outside the major urban centre. All participants were practicing family physicians except for three participants who were completing residencies. The participants ranged in age from 31 to 70 years of age.

Approximately two-thirds of the physicians participating in the focus groups had been using the Internet for 2 years or more. Twenty-three of the participants had a computer with Internet access at their office. All but one participant had a computer with Internet access in their home. Fourteen of the participants had visited the CTFPHC web site.

Recruitment:

Family physicians were recruited for the focus groups using a family physician e-mail discussion group called FERN (**F**amily medicine **E**ducational and **R**esearch **N**etwork). The Thames Valley Family Practice Research Unit (TVFPRU) at the University of Western Ontario, London, Ontario, sponsors FERN. Currently, there are just over 150 area family physicians that are members of this e-mail discussion group. These physicians are provided with an e-mail account and software to access the local University server. TVFPRU provided permission to our research team to use the list of FERN members.

The FERN e-mail discussion group list was chosen as the initial recruitment vehicle because all FERN members have access to the Internet in some form. Although access to the Internet does not guarantee Internet use, the research team felt it was reasonable to assume these physicians were somewhat familiar with the Internet. Limiting participants to those with at least some understanding of the Internet would help focus discussions towards how information should be presented on the Internet.

Initially, a general e-mail invitation was sent to members of the FERN list. This general invitation was followed by a maximum of two personal e-mail messages. These e-mail messages were sent from a local family physician who is also a member of our research team. The research team felt it was very important that the invitation to participate in this project come from a FERN member and a peer. In the second phase of recruitment, two of the research team members telephoned physicians on the FERN list to complete the focus group recruitment. Four participants were recruited by telephone call, the remaining 30 were recruited through e-mail.

Consumer Focus Groups

Four consumer focus groups were held in the month of May, 1999. There were a total of 39 participants; 22 male and 17 female. One focus group was composed of all male participants. The remaining three focus groups were a mix of male and female participants. Three of the four focus groups were held at large workplaces in a major urban centre. The fourth focus group was held in a small rural community, with patients from a local family practice.

Approximately two-thirds of the focus group participants had been using the Internet for two or more years. Twenty-six of the participants had a computer with Internet access at their workplace. All but three participants had a computer with Internet access in their home. Three of the participants had visited the CTFPHC web site.

Recruitment:

In each of the focus group locations, a contact person at that location was responsible for recruiting the focus group participants under the guidance of the project coordinator. In two of the workplaces, a general invitation to participate was distributed to all employees by e-mail. In the remaining settings (urban workplace and rural family practice) an invitation to participate was given to individuals selected by the contact person at that site.

Each potential participant was required to answer a few questions to determine his/her eligibility for the study. In order to be eligible, the potential participant had to be interested in participating in a focus group and be between the ages of 35 and 65. Furthermore, they had to have experience "surfing" the world-wide-web and browse the Internet at least 2-3 times a month (Appendix 5).

As an incentive to participate, a $40.00 gift certificate to a bookstore was offered to participants. The research team did not want to bias the sample towards individuals who wanted a monetary reward. Therefore, the amount of the gift certificate was not disclosed on the recruitment e-mails and brief fact sheet. However, there was full disclosure of incentives on the information sheet given to participants at the focus group session.

Consumer Advocate Key-Informant Interviews

Three key-informant interviews were conducted with consumer advocates. One of the key-informants was from the field of public health. The other two key-informants were from non-governmental organizations. Members of the research team gave names of potential interviewees to the project coordinator. To get potential participants from non-governmental organizations, the project coordinator called the provincial office and asked to speak to the person responsible for the development of consumer health information. The project coordinator contacted the key-informants by phone and arranged an interview time.

Focus Group and Interview Conduct and Analysis

The project coordinator assumed the role of focus group moderator and key-informant interviewer. For the focus groups, a staff member of the CTFPHC acted as the assistant. The focus groups ranged in length from 1 hour to 1 ¾ hours. The key-informant interviews were approximately an hour in length. All focus groups and key-informant interviews were audiotaped and transcribed verbatim.

Following the focus groups, the moderator and the assistant completed debriefing notes. The moderator then read the transcripts, and using the transcripts and debriefing notes prepared a list of key words and themes. Following this, she wrote a summary of the physician and consumer focus groups. The summary was then read and verified by the assistant moderator. The same process was completed for the key-informant interviews, without the involvement of the assistant.

Results

The study results are presented separately for each group of interviewees - the four focus groups each of physicians and consumers, the three consumer advocates and the five interviewees from other organizations implementing consumer health information initiatives. The first paragraph of each section is a summary of the findings from that group, followed by the general points made by participants for each focus group or interview question. The points presented are those that were generally agreed upon by the category of respondents, synthesized across groups/interviewees. Points that did not receive general consensus are not included, unless indicated. Representative quotations (in *italics*) from participants are included for each point to give the reader a sense of the comments made.

Physician Focus Groups

Summary

A common theme to all physician focus groups were the barriers that time and technology posed to accessing information from the Internet. Generally, physicians would look for information on their own time, before or after seeing patients. When they did go to look for information it was usually after a number of patients had asked similar questions.

Physician participants felt a good index system would be the easiest way to find the answer to their specific questions. Generally, they would search for information by disease, organ system or screening test. If they were looking for patient-specific information they would look for information based on age, gender and family history.

Focus group participants wanted a simple web site design with text-based information and minimal graphics. When on the web site, the participants wanted quick access to the summary of the recommendations with internal hypertext links to more detailed information such as a summary of the evidence, explanations when evidence is unclear and a reference list. The summary information should include the date and grade of recommendation. Participants also wanted links to external web sites and information that they could print and give to their patients. Being able to print web site pages was important to these participants.

Focus group participants also recommended strategies for increasing physician use of the site. These included offering CME credits and incorporating CTFPHC recommendations into electronic charting systems.

Use of the Internet

Most participants described the Internet as an enormous storage place of information; some useful, but some of it "garbage." As a result, they expressed the challenges of efficiently using the Internet to find specific, credible information to answer their questions.

> *There's a lot of volume there, which probably you're looking for a needle in a haystack if you actually want to find something useful*

However, some expressed sheer excitement and enthusiasm about the accessibility of information on the Internet.

> *I love it, just love it! All kinds of stuff that I never thought of and you can follow that up . . . just the access, the accessibility of information across the world, it's amazing.*

A common theme to all focus groups were the barriers that time and technology posed to accessing information from the Internet. Both the time it takes to access the world-wide-web and the time to search for information on the Internet were barriers for the participants, many of whom said they would not use the Internet to access information while seeing patients.

> *We have a computer at the office but I don't think anybody ever goes online because it takes too long. If I make a note of something that I do want to look up, it's at night when I have more time, because I tend to get lost looking for what I want, going through and finding what I think is the right answer. I mean I just don't have that hour and a half in between patients. I don't think they would be happy with me.*

If they really needed the information quickly, many participants still looked for information in a textbook.

> *Like I've had a few things where I've tried to look up, and the more specific I want to get the more mess I'm trying to get through and usually I can't find anything. I hardly ever use the Internet actually to pull up information. If I really need to find something quickly I just pull the Harrison's out. It just seems I can find everything faster.*

Some participants also suggested there was much less urgency around prevention questions compared to treatment or diagnostic questions.

> *I think for the Periodic Health Review too, there are not very many questions that are burning questions . . . . If you're looking at screening and preventive issues, I mean if I can tell you right now what the recommendations are on pancreatic cancer versus telling*

> *you tomorrow or giving you a call next week, I mean it really doesn't make any difference that way.*

The actual search for answers to prevention questions raised by patients would often happen after the same issue had been raised by a number of patients.

> *You've had six patients this week ask about PSA. That's kind of the impetus to go and review it, review what the latest recommendations around PSA are, just as an example, and then you kind of refresh those, and there it's also kind of a refresher opportunity, I guess. But I don't see using it on a regular basis, except in a few cases.*

Time as a barrier was very closely related to the limitations of the current technology. Most participants described their frustration with accessing the world-wide-web through the local university server using a modem. Although many of the participants felt the future would bring about changes to technology that would mean almost instantaneous connection to the Internet, some were skeptical that these advancements would change their current information seeking behaviours. Others were concerned about their ability to afford this technology. Because of these barriers, participants in two of the focus groups talked about regularly updated CD-ROM versions being useful at the office when they didn't have the time to dial-up their server, enter their password and gain access to the Internet.

> *The CD-ROM would be really good as long as it was updated every three months. That would be great. That would save you loads of time.*

In one focus group there was a large debate about being able to access the information for "free" on a web site versus quick easy access to information using a CD-ROM purchased for a fee.

Prevention Information Needs

Participants' needs for prevention information were often prompted by patients' questions regarding screening for specific diseases based on their family history or age.

> *Young women with family histories of breast cancers coming in requesting mammograms, when they're really too young to have them done. I find that our guidelines are a little different than the States, and they come in with a Good Housekeeping that says you should have a couple in your forties and every year in your fifties, and they even do them sooner than that. Then I have trouble convincing people that, "Well no, really they're not that useful, and no, maybe you shouldn't be having*

> *them." It would be nice to have a way of communicating that to people so they would believe you, that you weren't just putting them off.*

A second reason for accessing prevention information, discussed in two of the focus groups, occurred when participants were looking at standardizing preventive actions for their patient population.

When asked to identify the type of information physicians wanted to see on the web site, a few general comments about physicians' information seeking behaviours were made. First, participants generally found it harder to scan information on a computer compared to a paper copy.

> *That's the problem with the computer is that you can't scan. I think with articles you can scan, right? You can flip quickly and scan. Computers don't really lend to that because you've got a little box and you've got to keep clicking over and clicking over. I find that's one of the problems with computers.*

Second, physicians were often trying to find a specific answer about a topic they already knew something about, as opposed to looking for general information on a new topic.

> *I think once people are in practice for a long time, I mean basically you are looking for one piece of information . . . . like you want a dosage, or you want the treatment, you don't want all the background music.*

It also became apparent that issues of credibility were very important to the participants.

> *Credibility has to do with how recently is it updated, how often is it updated, who are the authors of the web site, you know, is it peer-reviewed stuff that they've put on it or is it non-peer reviewed stuff. Basically the things that you look at in a journal article you have to look at a web page the same way.*

Accessing Information on the Web Site

Across all four focus groups, it was clearly expressed that physicians wanted to be able to get accurate and current information fast.

> *I think that in many ways, what we hope to get from clinical practice guidelines is that sort of rapid access to a summary of the state of the art, current, cutting edge knowledge related to what we're looking at, be able to get in, get it, and get out fast.*

Most participants felt fast, easy access would be best facilitated through a strong indexing system. Although most participants indicated that a key word search would be extremely helpful, they thought priority should be given to developing a good index.

> *If it is set up logically you don't need key words because if you're looking for, you know, pick whatever key word you want, it usually relates to a disease or something. If there's a logical organization to the site [index] where it is focused on either the disease or the organ system, then you should be able to get through there and find that area almost as quick.*

Participants indicated the guidelines should be indexed by disease, organ system and by screening test. In addition, participants also wanted to be able to access age and sex specific guidelines and guidelines based on the grade of recommendation.

In one focus group, participants clearly liked the idea of having an interactive means of finding the information they were looking for. They wanted to be able to enter simple patient characteristics such as age, sex and various risk factors, and have the computer automatically generate the information from the recommendations they needed.

> *I would like to see something where you could take your patient, you know, patient age, gender, if they have any risk factors present, things like that. So instead of getting your full guideline, it has this built into it. So age is up here, and if these symptoms are here and those symptoms are there, to be able to say here's an easy history. You have ten check marks, and have the machine say well here is a little bit of the guideline that applies.*

Participants in this focus group, and one other group, also suggested having a private discussion area for physicians.

Format of Information on the Web Site

There was agreement among the four focus groups about what type of information participants wanted on the web site and how they would like that information presented. Participants wanted a quick text summary of the recommendations, with the date of the last update and the grade of the recommendation clearly indicated.

> *I'd just like a summary and then knowing that if you really did want to look at the whole thing, you can. Just sort of a brief summary.*
>
> *I want the date that the recommendation was made. I mean for example, PSA is a good example, we've got the recommendations as they are, whenever they were written, and I have got a funny feeling that that's going to change. I don't know which way it's going to change or how, but I think that my information on that when I look up in the Red Brick or look it up on the web site, it is probably less than current . . . I just need to know what the date of this review was because things are changing quickly.*

> *You want some idea of . . . how good is the information even within the suggestions, some assessment . . . . rating the quality of the evidence.*

Generally, participants did not want to see a lot of text on the screen. While a few participants recommended including a flow-sheet with quick yes/no questions, most participants preferred a brief text summary of the recommendations, with links to more detailed information.

> *I see this as levels. So for instance, level one is what are the guidelines for breast cancer screening. You know? I'd like to be able to just click on that, read what it says and get out of there. Now if I find that I want to go farther, I'd like to be able to expand on it and maybe look at where they came from and what the text was, what studies you referenced and so on. But I don't want to have to see all that at first because maybe all I'm asking is a very simple question like should I do this test at this age or not.*
>
> *You could have certain key words in that summary as a guideline that you could just click on. So if it's age, it would just take you to the age issue pertaining to that guideline, or if there were other risk factors or family history you would just point and click on that.*

In addition to age and sex specific information and information about various risk factors, participants wanted links from the brief summary to the evidence, patient information, and other organizations' guidelines on the same topic. Participants recommended links to reference lists, abstracts, or full-text versions of the evidence.

> *I also want to be able to actually go to maybe the papers, or at least find out the names of the papers and their authors and so on. I may want to go even further, but I don't want that on my first view because it's going to be too much information.*

They also wanted some explanation of why the recommendations were made.

> *Have a short brief statement about the key evidence which led to the recommendation. Oftentimes there's . . . 60 randomized control trials. I mean basically you don't want to know all about those trials, but you want to know the bottom line as to where the evidence is and why it is that the recommendation is the way it is.*

Most participants recommended including specific patient information on the web site.

> *One important advantage of having a specific site for screening recommendations based on evidence-based medicine is also the educational aspect of the site, not just for physicians, for patients. Patients go to the Internet and patients navigate through the Internet, and then they come to the office with a stack of papers that they've printed out from the Internet with the most crazy and conflicting opinions. If we manage to manufacture this site that is useful for physicians and also has an educational value for patients, we will go there.*

These participants wanted clear and understandable patient information that they could print out for their patients or direct their patients to on the Internet.

> *There may also be some materials that if somebody has a history of breast cancer or ovarian cancer or has concerns about prostate cancer, there might be a one-page printout that would be a patient education resource. You could basically say, "Here is what the Canadian standards are saying to the Canadian public and if you want to just read this over to help you to make a decision about whether to have the test or not.*

Alternatively, some participants did not think there was a need to have separate patient information. In one focus group a few participants argued that it was the physicians' responsibility to sit down with the patient and translate any difficult words. Others thought this was not realistic, and suggested patients may accuse physicians as "hiding behind [their] language."

Overall, most participants felt that the public should have access to the same information as the physicians. In addition, specific patient information should also be available; information written at a lower reading level and using terms with which the general public are familiar. Some participants felt there should be some sort of "disclaimer" on the physician information for the public to read.

> *I think theoretically patient information is supposed to be written at a grade seven educational level. On average the stuff that physicians get, tends to be very muddled for patients, but I think the patients like to have access to what physicians have access to, . . . so I don't think it should be limited, or you should have a secured password to get to the physician part. I think both should be available, but you might want to tell the patient that a lot of the other stuff is medical talk. Just like legal talk is Greek to us, medical talk may be Greek to them.*

Participants in all of the focus groups indicated that links to related guidelines from other organizations would be helpful. One group wanted a limited number of credible links with the Canadian sites clearly marked. In two of the focus groups, participants indicated that they would like an actual comparison of the guidelines with potential controversies highlighted and explained.

> *Actually, one thing that might be interesting, and it would be a lot of work . . . , but to put on all the guidelines. Like here's the American guideline, here's the Canadian guideline . . . . and this is what's different. Here's what we think about the difference.*

> *Or have a controversy section. You know, these are the unresolved issues, or these are the current controversies specific to this guideline.*

Throughout the focus group discussion, a number of other possible links from the brief text summary were identified. These included: frequency of tests; counseling strategies; explanations of the grade of recommendation; related guidelines within the web site and names of the reviewers. In addition, one focus group had a lengthy discussion about the challenges of explaining population-based information to patients. The number-needed-to-treat statistic was said to be useful, and should be included in the recommendation. In another focus group it was indicated that the Task Force web site should include a disclaimer for legal reasons.

> *The other thing when you look at it medico-legally, I agree that lawyers would take you to court and say, "Why didn't you follow those guidelines?" There should perhaps be a disclaimer that these are guidelines and not necessarily rules, and when you practice medicine these are just guidelines.*

A number of more general links within the Task Force web site were identified as useful. These included descriptions of the Task Force methodology and identification of the Task Force funding agencies, members, and reviews in progress. Participants also wanted quick links to newly updated material on the web site.

In general, participants wanted the format of the web site to be kept simple and clean. Most suggested that graphics should be limited, or made optional, due to the amount of time they take to download.

> *You don't want too many pictures. You don't want pictures of the cholesterol molecule in there or something. But the logo in colour that looks jazzy and it downloads quickly, and it's an [attention] grabber I think. That kind of graphic is good.*

Two of the focus groups emphasized the need for information to be printed on one-page documents. Participants in these groups wanted print materials, both for themselves and their patients.

> *Any summary that you are going to print out, if it's a summary for a patient or just a summary, it would be nice if it printed out on one page.*
>
> *I think it's also our comfort level. I think a lot of us are more comfortable reading paper.*

Physician Use of Web Site

Focus group participants also recommended strategies for increasing physician use of the site. One focus group liked the idea of offering CME credits for spending time looking around the CTF web site.

> *The Task Force could work out something with the College, you know, saying this is an innovative home study program, and we want to encourage people to use these latest guidelines, and reward people for doing it. It might be an extra incentive to encourage people to access it*.

Participants in two of the focus groups suggested developing templates to be linked to office electronic charting systems. These templates could be available in a variety of document formats to match commonly used chart systems. They could be modifiable to suit the individual practice needs; with periodic updates as new recommendations are developed.

> *A better enhancement . . . would be if it could interface with your office system and put prompts on the sheet so that when you see the patient is there, it says, "Hey stupid, this is supposed to happen, this lady hasn't had a pap smear in X number of years".*

Consumer Focus Groups

Summary

Participants were asked questions about what type of information they wanted on the Canadian Task Force on Preventive Health Care (CTFPHC) web site and how they wanted that information presented on the web site. In addition to talking about clinical prevention issues, participants often talked about understanding illness and treatment issues. When encouraged to talk about prevention, participants wanted to know what they could personally do to prevent disease as well as what their doctor could do.

Despite some challenges in focusing the groups on clinical prevention, participants presented a number of suggestions for the content and design of a consumer-based web site. Other issues discussed by the participants included issues of trust on the Internet, marketing of the web site, and how they used health information from the Internet.

Participants gave a lot of useful information regarding both the content and design of a consumer-based web site. They wanted a site that included information they could understand in a language familiar to them. It was also important to include evidence to support the recommendations made. When evidence was unclear, they wanted the facts clearly stated so that they could come to their own decision. Some participants suggested that hearing about other people’s experiences would be extremely helpful.

Participants wanted a site that could be navigated easily by novice computer users. They gave a number of suggestions for easy access to information by index, searching features, or an alphabetical listing of topics. It was evident that consumers wanted a well designed web site including graphics, colour, and text to capture the interest of the users. Participants recommended linking to other web sites as a means of providing access to information beyond the scope of the CTFPHC.

It was apparent that participants’ trust of information on the Internet was often determined by the source of that information. They strongly advocated marketing the CTFPHC web site in physician offices and health care facilities, as well as advertising in the mass media. These focus group participants often printed health information from the Internet to take into their physician. Internet information also helped them to become more informed and know what questions they should ask their doctor.

Developing Consumer Content for the CTFPHC Web Site

In all four of the focus groups, the participants gave some clear messages about strategies to keep in mind while developing the content of the web site. Participants consistently asked for messages to *"use the KIS theory, Keep It Simple"* and *"laymen's terms."*

> *It should be written in laymen's terms so it is readable and understandable . . . . I just hope that they understand that the information is not just going to doctors now, it's going to the public, and it has to be understandable by the public and written in language that they would understand.*

Many focus group participants felt easy access to definitions of medical terms was a necessity.

> *You may even want highlighted words that you can click on and it will do a little definition of that word, so somebody doesn't have to stop and go, "Well what's this word ?" or "What's that word?" They can just highlight that little area . . . . Just don't get the definition out of the medical dictionary.*

Participants wanted to know what clinical prevention issues they should be considering based on their age, gender and family history. Of these characteristics, age was most consistently mentioned.

> *Why couldn't they come up with some kind of a general guideline for people, for instance, age 30 - you should be looking for this. Age 40 - you should be looking for this. Age 50 - you should be checking into this. Just general guidelines and then if you have a legitimate concern you could go to your doctor and say, "Should I be investigating this or is it something I don't have to worry about yet?"*

Primary prevention was a key concern of all participants. They wanted to know how they could prevent getting sick in the first place. For some participants, this was the only important type of information

> *"Nobody really cares about screening, tell me you're going to prevent something. Yes, being proactive is the way it should be."*

However, many participants wanted to know about screening issues. In particular participants wanted to know how frequently screening tests should be performed and the reasons why the tests should be completed.

> *There has been lung disease in the family. So I'm interested in looking at [information] from the point of how often should [I] have an x-ray done. So it's getting that information, and I would certainly go to the Net to see if there's been any studies of about how often I should have it done, and the same with mammography and that sort of thing . . . . is it once every year, once every five years, is it based on age, genetics? Until you see these studies and what they have come out with then it is hard to tell on that type of thing. But . . . all of us are interested in stuff like that for different reasons.*

Participants wanted documentation of the evidence on the web site. *"I want this information on there backed up with, 'Here's the research behind it.'"* They also wanted to know when the evidence was unclear or uncertain.

> *Put the argument in there . . . . all you can do is to give me the information, then I am going to have to make a decision based on that and what my lifestyle is and [other factors].*

Similarly, when participants were asked if they wanted the recommendations to be given a grade representing the strength of the available evidence, they generally felt this was useful, but again added that they would make their own decisions.

In one focus group, participants suggested users should be informed that the information provided is based on general population statistics. These participants suggested users should be advised to consult with their own physician.

> *I think you have to make it clear that that information is obtained on information from the general population of Canada. That has to be very clear that this is how it was obtained, but you have to consult your own personal physician for your case. I think that's fair. Because you certainly don't want some one saying, well with the risk there I might not go. I might decide not to take that based on the information on the Internet. I think it has to be very clear, there has to be qualifying statements in there to consult the physician.*

In two of the four focus groups, participants suggested including personal stories from other patients.

> *I'd like to hear some personal stories too, like get it down to my level, not just the professional level. I would like to hear the personal side of it and what somebody else may be going through and how they got help.*
>
> *I like the idea of hearing people's stories because you feel less alone.*

Design and Format Issues

Many of the participants' comments related to design and format concerns of the web site. Generally, they wanted a web site that was easy to use.

> *A web site itself should be as simple as possible so people can go in, and even those who have little computer knowledge can go in and navigate through it easily.*

Participants identified a number of areas of importance including web site navigation, easy access to information, appearance, interactivity, and links to other web sites.

Web Site Navigation

Participants wanted to be able to navigate quickly to the recommendations made by the CTFPHC.

> *I think probably some recommendations at the front. I mean that's usually what I'm looking for, especially if it's for preventive, if you can have those on the first page or very close to it, or even have a little menu or something that says give me the recommendations right away. Because that's what I'm looking for in a lot of cases . . . then you can go back [and look] at the detail.*

They also wanted to get back to the home page quickly and easily.

> *But also for navigation purposes, if you are at the top and you want to go back to the main menu you don't want to go back 200 times to get back to the main menu, you want to go right to it . . .You want to jump around as easily as possible. That's a nice web site to get around in.*

Participants indicated that the web site should include dates on the recommendations, the date of last up-date on the home page, and a section on the web site that would quickly identify new information.

> *Have a "Recent Topics" or something at the bottom where if I am a regular user I can go right down to something that is brand new and I can click on it right away.*

Easy Access to Information

A number of suggestions were made on how to provide easy access to the information. Participants' suggestions included: (1) an index system; (2) an alphabetical listing of topics; and (3) an internal search function. One participant suggested using a search feature where users could enter the phonetic spelling of a word.

Of all the suggestions made, participants most frequently discussed a web site index. Participants indicated that a good index system was critical to help users navigate through the web site.

> *Indexing by topics or functions, like breathing, or digestive, so that you would have a way to get into it when you know the issue.*

One participant suggested using a graphical index system where users would click on a specific body part to access further information.

Web Site Appearance

Overall visual appearance of the web site was very important to the participants. Participants wanted a site that was *"appealing to the eye"*

> *You want something that's a little catchy, [so] that you say, 'Gee, I want to look at that!'"*

Throughout the four focus groups, participants consistently indicated that they wanted graphics and colour on the web site.

> *I think there should be more graphics on it because most patients understand what is going on by the picture, not by the words. If you show them a picture they're going to understand it. If you show them words, some of the time or half of the time they don't know what they're talking about unless they're very well educated on the subject.*
>
> *Colours, the way it's presented, 3-D, something that really jumps out at you and makes you sit up and look. I think the first lines, the wording on the front page has to give a good explanation as to what you are going to find.*

Some participants also suggested incorporating audio and visual effects on the web site. However, many participants would qualify suggestions for graphic and audio/video features with cautionary notes about increased download time. Speed of download was a concern for users, but the stronger view was that *"all text gets boring."* In one focus group it was suggested that CTFPHC provide both a site with graphics and a text-based site, so users have the choice of which site they prefer to use.

Participants in one focus group suggested that getting users' attention would be difficult in the area of prevention. Creative use of text and graphics would be needed to grab people's attention.

> *I think you have to be very creative on the preventive stuff, like "Turning 40 soon? Click here!" or "You are your mother" . . . . something clever to get people to go in and self-direct themselves.*

<u>Interactivity</u>

Participants suggested a number of ways to create an interactive and dynamic web site. Participants wanted to enter some personal information and have the computer generate a list of CTFPHC recommendations relevant to them.

> *I would look at it, I enter my age, something that says what's your age, so you put it in there and it says well your age is this, then you should have done all this. It doesn't have to be in great detail. You want it summarized first and you drill down as you see fit . . . . and then maybe a bit of family history if there is a history of cancer or a disease or diabetes.*

As suggested in the above quote, focus group participants consistently stated that they wanted the information presented in layers so they could choose how much and which information they wanted to access.

> *Let [us] dig [for information] I can get the KIS (keep it simple) information and then I can go deeper if I want to go deeper, and then I can link to somebody else's [web site].*

Another interactive feature identified by the participants was a list of "Frequently Asked Questions." This would be a location on the web site where users could ask questions. The questions, along with answers from the Task Force would be posted on the web site for other users to read. Although some participants suggested developing this into a "chat room," most participants thought it would be best to have questions and answers monitored by the Task Force staff.

> *Also, a FAQ site or a question/answer board would be nice too, because people may have a question of a G.P. or somebody. So whoever is monitoring [the web site] could go in and answer the question or could tell them where they could go to get that information from.*

One focus group indicated that creating an interactive site would enhance the learning opportunities for the site users. Although the group initially entered the discussion by suggesting games would be a good way capture the attention of younger users, this participant thought interactive features would be important for all users.

> *Make it more interactive, because I think that is how a lot of the younger generation learn. Actually there are a lot of adults that, for whatever reason, everybody has different learning [styles] — to my understanding, some are visual, some are auditory, and there are kinetic learners. If we can somehow entice each of those [types of learners], not just focusing on one, but something in each area . . . I think that would be helpful.*

Links to Other Web Sites

In all focus groups, participants suggested the CTFPHC web site should link to other web sites having relevant information.

> *Also if there are categorized links with other information that deals with what you're looking for. I always find that, if I go to one site, they are always linked to other sites, and they are categorized by subjects and it's nice to be able to move around that way . . . . specific links, not just general.*

One focus group recommended that links to other sites include a disclaimer and a brief evaluation of their site.

> *Have some links to other sites but have a disclaimer that says, you know, "This may be an interesting site but we can't guarantee [the credibility]" I think that's the thing. Maybe if you also have a site that says "Here are the things that we have found out that are questionable"*

Throughout the focus groups, participants had a strong interest in linking to other Canadian web sites. Participants also felt links to other web sites would enable users of the CTFPHC web site to have quick access to lifestyle information such as nutrition and exercise.

> *This lifestyle issue is one that's pretty big and I can see where that could expand into a lot. There's all kinds of stretching and exercise but if you had somebody that knew, say they screened the good ones [web sites] and all that and then it had links provided that would be pretty useful.*

Trust

The issue of trust arose spontaneously in two of the focus groups when participants questioned credibility of corporate web sites. Generally, participants did not speak favourably about corporate web sites, especially drug companies.

> *My parents came back from Florida . . . armed with a whole list of things that they were supposed to try for this and that and the other thing. And my mom had also brought back some new headache stuff . . . I said why don't we just go take a look on the web . . . . Guess what happens, the first thing that comes up, the corporate web site. Can you believe the corporate web site? . . . . They're marketing, it's a sale pitch.*

When focus group participants were asked specifically about what sources of information they would trust, three focus groups identified consumer advocate groups such as the Canadian Cancer Society and the Lung Association as credible sources of information.

> *The Lung Association, that sort of thing would be I think a more reliable source than just Dr. Whoever who has decided to put his opinions out there on the web.*

Well-known organizations such as the Mayo Clinic and governments were also identified as credible sources.

> *I would look at something like the Mayo Clinic or Johns Hopkins Hospital, and those kind of institutions. They give credibility. I think a federal or provincial government has credibility.*

However, some participants were more skeptical towards information from governments.

> *The government is saying give us the research and tell us whether this drug is good for you or this chemical is good for you. . They are going to the people with a vested interest in telling them "Yes, it's good for you."*

One participant indicated a general distrust of information on the Internet.

> *I don't even know if I would go a web site for anything like this, personally. I think if I was concerned I would go [directly] to the Cancer Society, Heart and Stroke Foundation, and get medical information from them. I don't even know if I'd go to the Internet because . . .there is no control in place and anybody could put anything on there.*

In contrast, this participant was not concerned about the credibility of health-related web sites.

> *I'm not sure credibility is such a large issue. You know there are a lot of hokie things on the Internet but they're not in serious areas like Medicine . . . .Usually you will find that there are pretty reputable people that do a lot of work putting this information in. So I'm not sure that credibility bothers me all that much.*

Collectively, participants identified a number of issues that would increase their trust of a web site. These issues included: (1) if the organization was known to them; (2) if they saw the web site publicized in their doctor's office; (3) if the web site identified the sources of information, including the references used; (4) if the web site did not include corporate advertising.

Marketing the Web Site

In all the focus groups it was suggested that efforts should be made to market the web site to the general public.

> *But I think the trick is to publicize the URL address because when you go through the search engines, I don't find those terribly successful myself. I end up in some really weird spots asking for certain things. It's just better to have the actual address and you get to go there any more, because there is so much stuff on the Internet.*

In all the focus groups, participants recommended advertising the web site on posters and pamphlets in physician's offices and other health care facilities. Media advertising through TV and radio was also recommended, although one participant indicated that it was difficult to write down a web address when listening to the radio and driving a car.

Use of the Information

Participants consistently talked about using health information from the Internet as a second opinion. They also suggested that they might have more time than their doctor to find this information on the Internet because it is of personal interest to them. Often, participants would print information from the Internet and take it to their doctor. The information helped them to know what questions they needed to ask their doctor.

> *In getting more information at least you can ask the intelligent questions to your doctor, so you have a little more background."*

Some participants also used information as a means to prepare themselves psychologically and emotionally for the issues they would have to face. Participants talked about this in terms of receiving information about treatment processes in order to reduce their anxiety.

> *It was a comfort to actually the whole family to know exactly what the procedure was and how they were going to do it. It really is a great comfort. Then you don't worry as much. So that was a big help . . . . It removes the fear a little bit because you're not ignorant.*

Key Informant Interviews

Summary

For all three key-informant interviews, a great deal of time was spent discussing the process of developing patient information materials, with a predominant focus on how they obtained input from the patient or target population. This input was gathered at different stages in the process, both before the materials were developed, in order to get an understanding of what the consumer/patient issues and information needs were, and to test the materials after a draft had been developed. One of the consumer advocate organizations felt that their role was to provide the information that consumers needed while trying to provide a link to the information from the medical community.

Preparing targeted print information was a challenge for all three organizations, and each had developed different strategies to meet this challenge. One organization had started to develop customized single question/answer fact sheets; a step she felt went beyond targeting.

The key-informants felt the Internet would play a significant role in the dissemination of consumer health information in the future, although there was debate over what should be included on the Internet (print materials or interactive materials) and if there should be additional ways of disseminating information to the public.

All organizations were interested in the information that the CTFPHC had. However, similar to physicians and consumers, there will be challenges in disseminating the information to other health professionals and consumer advocates.

Obtaining Consumer Input

Throughout the key-informant interviews, it was apparent that hearing directly from the patient or target population about their information needs was central to the process of developing consumer health information materials.

> *We need to address what their concerns are or else we won’t move forward . . . we will be miles apart from what the medical community is saying and what the patient is feeling.*

Gathering this information was an important part of the process for developing all types of information materials, be it posters, displays, pamphlets or web sites. Data collection strategies such as focus groups, surveys, and interviews were used to complete a *"needs analysis."*

> *We will do the key informant interviews with the health professionals and others, just to get a sense of what the issues are from their point of view. But then . . . we will go out to the patient population and do some focus groups and gather information from them as to what they feel about the particular issue.*
>
> *We did a survey to determine how the people in that [target] group would like to receive information . . . we had been through all the focus groups . . . and we also went through a process of finding out what topics people would like to know about.*

Getting feedback from the target population after the materials had been developed was also an important part of their process. *"Then once the preliminary idea was set up, then we . . . got feedback from people."*

One of the key-informants elaborated on the changes in their process for developing patient information materials. The biggest change was in seeking input from the patient population.

> *It's changed. We have an array of print materials, and [in the past] it was taking the medical content, chopping it down to the grade six level, and churning it out there in some format . . . . which is "You need to know this. You should be doing this. And here's ten things you need to know." And yet, that's not what people are looking for sometimes.*

In their recent projects, listening to the patient population has been central to the development of their information materials

> *Our print materials will be very much focused on what questions they are asking, and even phrasing them in the way that they're asking them . . . . This way it allows us to customize the information so that we are answering their questions, and then maybe providing a few other critical details.*

By listening to members of the patient and target populations, the key informants learned a great deal about information gaps and the patients need for practical information.

> *We uncovered areas that there were huge gaps and before we couldn't quite understand why these people were not following the advice. But when we did the research with the patient population we just realized that it's not just about medication. It's not just about this, it's about living with this condition, and the*

> *many variables that come into play every day . . . and how do they deal with all of this.*

However, all the key-informants indicated that listening to the information needs of the consumers/patients demanded that they balance the consumer needs with what health professionals thought consumers needed to know.

> *There were some things that . . . people didn't want to hear about . . . . So it ended up in deciding that the [materials] would be a combination of what people wanted and what we [thought they] needed.*
> *So taking their thoughts and what they are interested in, but trying to weave [in] some of these other key messages. They are not even interested in some of the issues that we feel are so important.*

One of the consumer advocates talked about this balancing act in a broader way. She discussed the challenges of balancing the research evidence with the practical and political issues that affect patients and health professionals every day. As a consumer advocate, this was an issue she grappled with frequently.

The interviewees saw written consumer health information materials as the first step in (1) promoting healthy behaviour change, or (2) helping patients cope with a disease.

> *One of the things we've learned is [that] giving information alone won't create [behaviour] change necessarily, I mean for a motivated person it might, but you have to have motivation. So you have to develop motivation. People have to develop skills and there has to be an environment of support.*

> *Information is sort of a baseline activity, and for the [patient] [and] people living with the [patient] — and that includes family and friends, caregivers, parents, you know the group of people around the [patient], they cite information needs as being one of their most pressing and urgent needs.*

Two of the key-informants spoke of the challenges of measuring the impact of the information on patient outcomes.

> *We are just having some meetings with people who have expertise in evaluation to say, okay, what is it that we are trying to achieve? Do we really think that by having an interaction on the phone and supplying print materials that we can have an impact on their [patient] outcomes?*

Production of Consumer Health Information Materials

To some extent, each of these organizations hired outside consultants to help in developing consumer health information materials. The tasks contracted out varied from writing and graphic design, to needs assessments and market research by social marketing firms.

> *Once they had decided kind of the key information, she then engaged a professional design company . . . not for the message so much, because we still had to decide what we wanted to get out, but how to set up the [materials] and what would go on.*
>
> *When we make a decision that we are going to produce a resource, nine times out of ten we hire someone to write it. We tell them the information that we need for public use. We usually hire a writer to do it. They do the research and prepare a manuscript then it goes out for review and editing.*

Due to the numerous drafts and feedback opportunities, all the key-informants indicated that the actual development of materials took much longer than anticipated.

> *It's almost a shame to talk about it, but it can be eighteen months to two years [to develop a simple brochure].*

Throughout the interviews, the participants talked about their target audience and the different information needs of people. When specifically asked how they produced targeted written information, the issue was handled differently by the key-informants. The public health professional strongly advocated developing messages for specific target groups.

> *I think you really have to think about the stages of change theory. So what is your piece of information for the people who are pre-contemplators versus [contemplators] etc. . . . . and how would the information need to be there for the different people.*

For one of their projects, they decided to target potential "change agents."

> *And the other thing is you need to think about diversity in everything that you do. And often you walk a fine line between offending one group and reaching another group . . . you have to decide who your main target is. And we had this big discussion about doing everything for everybody . . . we finally decided that if you really want to make a change in society you have to change what is the norm in society . . . . So we decided that we are just going to aim to that group out there who is likely to pay attention and come, and that what you hope to do though, is you get spin-offs in that. You create that environment of support.*

Both of the consumer advocate organizations used their telephone information lines as a means to provide individuals with targeted information.

> *Well, you can never get it right for everybody . . . the information specialists talk to clients and they are highly trained professionals. They try to assess as they are speaking to the individual how much information is required, how much information would be helpful, and how much would overwhelm.*

One of the consumer advocate organizations developed written information at various levels to meet the different information needs of the patient or target population.

> *We talk about levels of information. We have a basic level and then there are people who want more details, and then more details, they are like fanatics . . . . That's where the challenge is. You can't say well it's only ten percent, I'll ignore them, but a lot of effort goes into responding to the information needs of that ten percent.*

The other consumer advocate organization is attempting a new strategy with their written information. They are trying to "customize" the information, which they saw as a step beyond targeting. In essence, they are creating a series of fact sheets that answer one individual question. The topics for the fact sheets were generated from the patients' needs identified in focus groups. The questions are written in the patients' own words.

> *We talked about targeting. It's much more complex than that. Once you get into the whole way of viewing a condition from that person's point of view, and it's different for each person . . . . You can't say we're targeting those women in this age group, because there are many different issues even for that segment of the population. So I guess we've said that as an organization we want to be understanding and expressing the views of this patient population. So that's what we need to be doing as an organization, and then trying to bridge the medical information and what the individual is looking for. And since we haven't embarked on this we don't know how successful we will be, but that's the kind of thing that it's completely — it's more than targeting, I think it's more complex than that.*

The Internet as a Vehicle for Disseminating Health Information

All the key-informants saw the Internet as a major vehicle for disseminating consumer health information.

> *More and more people are turning to [the Internet] for health and medical information. I think that unless we are there, then there is a great segment of the population that aren't [going to get the information] They aren't about to pick up the phone right away, and they're not about to come out to a group of healing seminars. But they'll go searching for the best information they can find on the Internet. Improving our presence on our web site, and having it very interactive too [will be important].*

Both consumer advocate organizations were moving away from printing volumes of brochures, and starting to use the Internet more and more.

> *We may just print that off [materials] as we need it, as opposed to having an inventory. I guess the other key area is the Internet. We know that people are going there. We know that with our site we are amazed that we are getting 65,000 hits a month on it, and it needs a lot of work.*
>
> *Our primary distribution is going to be through the Internet but what we are going to do is that we are going to distribute them outside of the Internet but we are going to download them from the Internet. So we are going to actually print them out, copy them, and give them to people. We are not going to print them [mass productions] any more and send them out to all of our units.*

However, while one key-informant believed the advantages of the Internet were the possibilities for interactivity, another saw value in using the Internet strictly as a dissemination channel.

> *The people from here who work in this area have gone to seminars and have had training opportunities and development opportunities around the web say that this is supposed to be the classic mistake that an organization makes, that is to put all of its print information on the web . . . . The web is supposed to be an interactive thing, and it's not supposed to be static. And people don't really get a lot of thrills out of [static information] — and I just think they are wrong. I just don't believe that. It is another way of disseminating printed information. There is a huge demand for printed information. It is absolutely, awesomely huge.*

The third key-informant felt it was important for the Internet to provide a link to a contact person or service and was concerned about how people without Internet access would get the information.

<u>Use of the Canadian Task Force on Preventive Health Care Recommendations</u>

For all the key-informants, having access to the Task Force's evidence-based recommendations was seen as a valuable resource.

> *For us, the hardest thing is to integrate knowledge and information. So if there has been any kind of scientific minds who have taken a body of evidence from a lot of different places and synthesized it into something — here's the best recommendation we have for health professionals — that is incredibly useful to us, because then you have that already done for you, in a sense, and you know where to go.*

However, similar to other professionals, they often looked for information on a need to know basis: *"You usually like information on a need-to-know basis but sometimes you don't know you need to know it."*

It was suggested that involvement in medical research or being part of collaborative process to develop the recommendations would play an important part in the adoption of the guidelines.

> *We were involved in recruiting for that study, we were also more aware of the study going on . . . . So by the time the answer comes out and they are saying this is stupid, don't do this, then we've been [involved] along the way.*
>
> *We've always worked in collaboration with other groups . . . . I'm just waiting to hear the outcomes [of one guideline we are involved with], and then all of our materials will be revised to reflect the screening guidelines and we will provide that information to the public.*

The public health professional interviewed also suggested providing examples of how the recommendations have been put into practice would be helpful for her.

> *If somebody has taken the information or made the effort to find something out and put it into practice and they can demonstrate results. That's what gets my attention.*

Organizational Interviews

Representatives from the National Health Service (NHS) in Great Britain and the Agency for Health Care and Policy Research (AHCPR) from the United States were interviewed by telephone. These agencies are both involved in the development of consumer information from evidence-based research. While not explicitly part of the present contract, it was felt that these telephone interviews would give the CTFPHC some sense of the processes used and "lessons learned" by these organizations, and would help us come to a decision about the feasibility of providing consumer information, and if implemented, avoid obvious pitfalls.

The individual interviewed from the NHS was working with the NHS in Scotland, although she previously worked with the NHS in England. In total, four people from the Agency for Health Care and Policy Research (AHCPR) were interviewed. Three were interviewed simultaneously about their involvement with writing and publishing “Consumer Guides” based on the clinical practice guidelines (CPGs) published by AHCPR. A fourth person was interviewed from the Put Prevention Into Practice (PPIP) program (described below).

Summary

All of the organizations interviewed had been involved in developing consumer health information from evidence-based reports. The main impetus for this was to have informed consumers (i.e. taking the first step in a larger process by providing quality factual information). However, while this was the main purpose of AHCPR, both the NHS and PPIP had additional reasons for producing consumer health information. NHS used evidence-based information to meet stated consumer needs in specific topic areas (e.g. prostate cancer screening). Taking this one step further, the PPIP program was trying to give consumers practical information and tools to help them change their health behaviours in accord with evidence-based preventive health care guidelines. Where possible, they tried to develop materials targeted to different populations.

For all organizations the development of consumer information materials was a highly iterative and lengthy process with multiple drafts and feedback mechanisms from a variety of experts and consumers.

Consultations with consumers were a central part of the development process. Most consultations were in the form of focus groups. NHS used focus groups for two purposes;

understanding patient needs and feedback on draft materials. Alternatively, AHCPR used focus groups mainly as a feedback mechanism.

Both the NHS and AHCPR are moving away from developing consumer health information from evidence-based reports. The NHS is hoping to play a more supportive role through developing the *Centre for Health Information Quality.* ACHPR started producing "Evidence Reports" as opposed to CPGs, and therefore will not be producing consumer versions. The PPIP program will continue to produce consumer health information, now based solely on the recommendations from the United States Preventive Services Task Force (USPSTF), the CTFPHC's sister organization.

Background Information on Organizations

Over the past few years the NHS has funded a number of research projects to generate patient information materials from evidence-based guidelines. The main purpose behind these projects was to inform patients so they could become more involved in decisions made about their care. However, as can be noted from this quote, there were many reasons for developing patient information materials.

> *There was a push towards evidence-based health care and so (a) we were more acutely aware of the distinctions between good research-based information and other information, and (b) we were looking at different ways of trying to promote effective health care and informing the patients and using the patients as change agents as one possibility. Then there was a general push towards improving the quality of information that is available to people. There were various things driving towards that; consumerism, the need for people to be able to give informed consent, [and] the notion that people should be participating in decisions about their own care . . . . I think the other thing was an awareness that more and more patients and members of the public were seeking health information.*

The role of the NHS in England and Scotland now appears to be more of a supporting role to encourage other organizations to develop quality patient information. For example, the NHS in England has developed a *Centre for Health Information Quality* to support the development of patient information that is clearly communicated, evidence-based, and involves patients. Furthermore, the NHS in Scotland is funding a research project to assess various processes for developing quality patient information materials.

> *Basically the project is to develop information materials . . . but along the way to compare the feasibility, yield, practical issues and costs of different approaches to trying*

> *to identify patient information needs, current beliefs, concerns, levels of understanding and so on. Also, different approaches to kind of quality assurance, to what we would broadly call peer review.*

The situation in the United States is somewhat different than in Great Britain. In the past, the Agency for Health Care and Policy Research (AHCPR) in the United States developed a number of consumer versions of CPGs covering a broad range of topics from prevention through to treatment. Similar to the NHS, the purpose of producing consumer versions was to inform consumers.

> *I think that originally, when they envisioned the guidelines they envisioned it as a program that would be for a number of audiences. It was also to ensure that we had informed consumers. . . . it was during the Bush administration and he had a great interest in science literacy. So part of this was to try to increase science literacy, and each consumer book was supposed to . . . provide a little science lesson . . . . And now the trend is more — it's kind of the same, it has just been relabeled something else where people need to be informed to be active in their care.*

However, AHCPR is now producing "Evidence Reports", as opposed to CPGs. Because many of the reports say more research is needed and don't include recommendations, AHCPR has decided not to produce consumer-friendly versions.

The PPIP program was established by AHCPR to address implementation issues around preventive CPGs. These issues included: *"provider confusion over who was recommending what, patient confusion over what services they needed, and also [to address] the provider being disorganized in their office, or having a lack of an office system to address preventive service delivery."* Initially, PPIP tried to incorporate guidelines from many different organizations. However, at this time it appears that PPIP will begin to focus solely on CPGs produced by the USPSTF. Furthermore, the publication of consumer versions of preventive CPGs in the United States will be done as part of the broader strategy to implement evidence-based CPGs through the PPIP program.

> *We are hoping to use the Task Force (USPSTF) as the driver to develop new PPIP materials based on what we find out are the needs for implementation of the USPSTF . . . . PPIP, when it was originally created, included recommendations of other authorities because we wanted to promote evidence-based guidelines by showing the differences between evidence-based guidelines and expert opinion based guidelines. So we've [now] made PPIP inclusive, and as we move along, we are looking at how PPIP can complement the Task Force.*

Content and Process Issues of Developing Consumer Health Information

Although all organizations based the consumer health information on evidence reports, the content of the patient information materials from these organizations varied. The NHS was trying to combine two objectives: (1) conveying the research evidence, and (2) addressing the needs of the consumer. As a result, they would sometimes look beyond the information in systematic reviews to meet the public's needs.

> *I think one of the things that we found is that we always started from . . . systematic reviews - they were to be the basis of things. But in fact, as soon as you started exploring the kinds of information that people want, or tried to explain things fully, usually the systematic reviews in themselves didn't cover everything you wanted to cover. So you ended up doing more bits and pieces, I guess research, or looking for information to complement what you've used. In many cases, the patient materials aren't just simplified versions of systematic reviews. And if you try and [write] just a plain English summary of a systematic review, it isn't the same as a piece of information that has been developed specifically to meet patients' information needs.*

Alternatively, AHCPR used the research evidence outlined by the Panels responsible for each CPG as the basis of the content for the "Consumer Guide." Although writers and editors at AHCPR would try to develop these materials from the consumer point of view, the basis for the consumer information was the CPG. This often meant compromises in terms of readability level of the final product.

> *When it [draft of Consumer Guide] would go back to the Panel, things would get undone because they wanted to make sure that everything was there that they thought needed to be there. So it caused some tension between what we thought consumers would want to know, and what the panel thought that they needed to know. This invariably raised grade levels of [the material] — it was a challenge, and it didn't always come out as simply as we would have liked.*

PPIP differed from NHS and AHCPR in that this program dealt specifically with preventive CPGs and its purpose was to address implementation issues. These materials focused on practical information and strategies to encourage both physicians and patients to follow recommended guidelines.

> *All the pieces that are included in PPIP have been documented to improve delivery of preventive services and to address some of the barriers to receiving preventive care. So the Clinicians Hand Book was created to provide practical information for clinicians about how to perform the services . . . . The patient materials were created because there were some studies done saying that if patients keep track of their own services they actually have improved service delivery.* Although there were differences why each

organization produced patient information from research evidence, there were a number of similarities in the processes the organizations would follow. All organizations described the process of developing patient information materials as highly dynamic and iterative: *"There were lots and lots of iterations."*

In addition to multiple drafts, developing consumer information materials involved numerous consultations with medical research experts, consumer organizations and experts in writing patient information.

> *It usually went through a couple rounds of going to people who were familiar with the research evidence for comment . . . we went to different kinds of health professionals, including say specialists and general practitioners. If there were consumer organizations we would use consumer organizations unless we knew that they were violently going to disagree with it, that it just wasn't worth eliciting [their thoughts] . . . . We usually sent them as well consumer health information specialists or providers.*

Consultations with consumers were central to this process. In most cases this was done through the use of focus groups. Because the NHS was committed to providing information to meet the patients needs, these focus groups were critical in terms of understanding both the patient information needs and the context into which the information would be received. Insights were also gained on how to present the material.

> *We've had focus groups in, if you like, two stages, where one is gaining current understanding, current perceptions, what words people tend to be using - are there any myths or do they already know quite a lot about something, that kind of thing. So the first half is eliciting information from them. And the second half is okay, these are the key messages that seem to be coming out of the research evidence on whatever topic we've gotten together to chat about, and trying to explore how they respond to the different bits of information, and how important they think it is, how they think it would best be presented, what do the implications seem to be for them. Writing, testing, even before you commit it for a first draft, just sounding people out about information.*

AHCPR used consumer focus groups after internal developers and the CPG panel had approved the draft. The focus group participants would be asked questions about the cover design, colours, type size, type layout, boxes, graphs and charts. In addition, consumer input was sought to ensure understanding of the messages being conveyed.[3]

> *There were always a good bit of changes that came out of the [focus] groups, but it wasn't really content-related as far as what the scientific recommendations were. It was*

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[3] The person interviewed from PPIP was not involved with the initial development of materials, therefore, she was unsure if and/or how consumer input was sought. They are embarking on a new project that will be seeking consumer input through the use of focus groups.

> *more how you said it to people because the science was all confirmed and verified by the panel . . . what the focus group did, was told us if what we said was what we meant.*

Regardless of the purpose for seeking consumer input, both the NHS and AHCPR talked about the boundaries of using consumer input. A representative from AHCPR indicated that focus groups are not a panacea. Information from the focus groups should be incorporated into the realities of what the research evidence says and the goals of the organization.

> *Focus groups are a good check, but they don't have to drive everything that you do as far as you [having] to answer every concern that they raised. It's a good gauge to know that yes, even consumers have identified that more research needs to be done, but I would try to overlay what they said they needed with what information you have . . . . There is a tendency with groups, to say. "The focus groups said this, and the focus groups want this" and that's not the best way to do it either. You also have to keep reality in there, and the science base. You try to hear their concerns and also do what makes sense for your organization and the science.*

For the NHS, development of patient information materials was often constrained by the defined purpose of their research project. Making those boundaries clear to the focus group participants was important.

> *If you then start going to patient groups or focus groups or whoever, and they start saying to you, "What we actually need is better information about post-operative care," then we couldn't deliver what they wanted because we were constrained by that . . . . When you're consulting people, let them know about the boundaries, the parameters within which you are working.*

Furthermore, the individual interviewed from the NHS thought *"some of the ideals of involving consumers in the production of information materials . . . needs a bit more thinking through, the political correctness needs teasing out a bit."*

From the above discussions, it became apparent that one of the major challenges in writing patient information materials is the gap between the information in the CPGs or systematic reviews and the information that patients or consumers want to know. The individuals interviewed identified a number of other challenges including the strength of the research evidence (what do you say when the evidence is unclear?) and various contextual factors such as the political and social climate into which the information is dispersed.

> *There were sometimes things that we couldn't discuss or make a recommendation on, because politically we had to stay away from that topic. So in that case, we usually*

> *would refer people to other sources, and that's why we found the resource section helpful.*

Changing Behaviours and Targeting Information

The individual interviewed from PPIP spent time talking about health behaviour change. She emphasized that PPIP was trying to provide a comprehensive resource of preventive services to create "awareness" of prevention issues, the first step on the behaviour change continuum. PPIP did not try to target information to individuals at different stages of the continuum.

> *When you look at "Stages of Change," one of the ways that behaviour change happens is that you need to create awareness of the issue - people need to know that they need to get a mammogram. My approach was that this was baseline [information] telling people what the recommendations were. Further pieces to evaluate where they were on the spectrum . . . needed to be tailored to the individual offices, so we didn't really address them in the booklet . . . It [the information] wasn't stage-based because you would have to create a lot of different pieces for every different stage that a person would be in. So we just are using these and they are meant to be a record-keeping mechanism for patients. Also, just a comprehensive resource of preventive services which is unusual because in the federal system there aren't very many groups in our country that provide comprehensive information about anything.*

Although PPIP did not target information based on the "Stages of Change," they did try to target the information by language and cultural issues. The interviewee strongly recommended targeting the information but at the time she acknowledged a number of challenges in creating targeted information.

> *Who is the typical American? There isn't one. There are lots of different literacy levels, and languages spoken, and even by English speakers there are a lot of different cultural issues. So it's very difficult to make a government publication. I mean you need to segment who your audience is, and it's hard to do that because when you segment to one you exclude someone else. But if you can break them down by ages . . . . We just segment them [patient information materials] on English speaking, I don't mean that this is necessarily [the best way], you have to balance cost with how useful the materials are to others. We opted for trying to have a lower literacy level on them so that we don't exclude people who can't read the material as well.*

The issues of behaviour change and targeted information were not major topics of discussion in the other interviews. For both the NHS and AHCPR, their target groups were people with the disease. Behaviour change issues appear to be more of an issue for information on prevention.

Format Issues

Although the interviews focused mainly on context and process issues, the interviewees also gave some formatting suggestions. For all of them, size of the brochure was important. They liked to keep the consumer information materials small so that patients could bring the information to the doctor inconspicuously. Furthermore, AHCPR found in their focus groups that people liked photographs as opposed to clipart and liked to see happy people. This was a form of reassurance.

CTFPHC was interested in learning if these organizations developed a template for their consumer health information materials. AHCPR followed a template because production of all the information materials was part of a complete stepwise translation of the CPG, to professional versions and pocketbooks, to consumer guidelines.

> *These were all parts of a series of guidelines and so they had to have similar products. They had to have certain core things.*

The items included in the AHCPR template were as follows:

- Definition of condition
- Overview of topic (e.g. anatomy lesson)
- Prevalence and occurrence of disease (reassurance they were not alone)
- List of resources
- Explained what might happen when they go to the doctor
- Included interactive features such as check lists and items to complete
- Tried to address their fears

The NHS did not follow a specific template, as each project was completed separately. The person interviewed felt it was important to have some flexibility in the design .[4]

> *It might be useful as a checklist. I guess if you are talking about headings, if there is flexibility to tailor them . . . but I don't think that I would be comfortable with being totally constrained by a template. I think partly it would depend what kind of topic, the range of the topics that get covered.*

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[4] The person interviewed from PPIP was not involved in the initial process, therefore did not know if a template had been developed. She used the original PPIP materials as the template for their revisions.

Production of Print Materials

All of the organizations contracted various parts of the production of consumer health information materials to outside organizations. Although this depended on the support services available within the organization, the areas of production that were commonly contracted included writing, focus groups, and graphic design.

Interviewees were also asked, if possible, to give estimates of the timeframe and costs for development of one patient information brochure. NHS estimated that it took about 9 months to develop a single information piece. AHCPR estimated that costs were $50,000-$70,000 (excluding printing) for each consumer guide.

It is interesting to note that one of the people interviewed from AHCPR suggested that CTFPHC should produce print materials as well as develop a web site.

> *I would personally recommend doing prints as well as Internet . . . I think you won't be able to reach everyone that way.*

Discussion

The information gathered from the focus groups, key-informant interviews and knowledge gained from the literature and interviews with similar organizations have given us a good understanding of the opportunities and challenges to developing a web site for both clinicians and members of the general public. The CTFPHC has a large body of useful and credible information for both physicians and consumers. This information provides a strong basis for developing a quality health information web site. However, a major challenge for the CTFPHC will be to develop simple and understandable consumer health information from the existing CTFPHC recommendations. The following section will discuss these opportunities and challenges in detail.

Opportunities

Internet as Communication Channel

The CTFPHC choice of a web site as a vehicle for dissemination of evidence-based clinical prevention information appears to have merit. Findings from the focus groups, the key-informant and organizational interviews, and the literature support the use of the Internet as a vehicle for disseminating health information to both consumers and physicians.

However, there were also suggestions that other dissemination channels, in addition to the web site, should also be explored. For example, the physician participants recommended having the information available on a CD-ROM, at least as a transitional phase, so they would not have to deal with technical delays in accessing the Internet. The barriers of time and technology in accessing the Internet were predominant themes in the physician focus groups and will be important for the Canadian Task Force to consider in future developments. Furthermore, some of the key-informant and organizational interviewees recommended that in order to provide equal access, print information should be available for consumers who do not have access to the Internet. However, it is interesting to note that some of the consumer advocate organizations are moving away from mass production of print materials and are considering using the Internet and printed pages from the Internet as their source of health information. There may be opportunities for the Canadian Task Force to use the web site information as the basis for providing information in other forms, including both print and CD-ROM.

Useful Information

The consensus from both the physician and consumer focus group participants was that the information that the CTFPHC provides is useful. Physician participants liked the idea of being able to use the web site as a quick reference tool. It is also interesting to note that participants in the physician focus groups brought up the need for patient information spontaneously. This indicates that not only would consumer health information be useful for the general public, it could also be used by physicians to help them inform their patients and encourage shared decision-making. In the literature, physicians are being encouraged to use computer-based patient education materials to enhance the doctor-patient interaction (Cooling, Kidd, & Sloggett, 1997)

Consumers liked the idea of having access to understandable health information. Consumer participants said health information helps them determine what questions they need to ask their doctor in addition to helping them make decisions about their own health care. Participants also indicated that information relieved their anxiety by helping them understand what was going to happen. The use of information to relieve anxiety is widely noted (Nadler, 1990).

Credible Information

With the expanding role of communication and information technologies, Internet web sites publishing accurate information will be an important resource for both physicians and patients (Coeira, 1996; Silberg et al., 1997). The largest cost is the effort to produce high quality information such as evidence-based guidelines (Coeira, 1998). Coeira (1998) suggests that " . . . it becomes cheaper to produce poor quality information the looks good than high quality information that is less well packaged" (p. 1469). As a recognized body providing evidence-based recommendations on clinical prevention, the Task Force already has high quality information in a synthesized form, ready to be adapted to a web site interface. Having this information will be a great benefit in the development of both the physician and consumer web sites.

For the physician section of the web site some simple format and design changes to the current site is all that is needed to provide physicians with an easy to use web site addressing their evidence-based clinical prevention information needs. For example, the physician focus group participants wanted quick access to a text summary including the date of last update and the grade of recommendation with the option to “drill down” or “dig deeper” for more information. The current CTFPHC web site could be adapted to present a summary of the recommendation with hypertext links to more detailed information including frequency of screening, reference lists, impact of age etc.. This idea of layering the information is an important design principle of organizing information on a web site (Quintana & Bardyn, 1996).

Furthermore, a strong index system could be developed based on the physician participants’ suggestions. Physicians said they accessed information by disease, organ system, screening test, age, and gender. A strong index system makes the information easier to find and actually increases the use of the information. Verhoeven et al. (1995) found that print sources with inadequate indexes were rarely used. This appears to be a feature of print media that will apply to information published on the Internet.

Other changes that were suggested by the physician participants, such as including links to other Canadian web sites and printable versions of the information, have already been implemented. It is interesting to note that in the consumer focus groups, particpants talked about printing the information to take to their physician.

For the potential consumer web site, the CTFPHC information would provide an excellent base for the development of evidence-based consumer health information. Furthermore, due to the scope of the CTFPHC information, the Task Force would be able to provide a comprehensive package of clinical prevention information to the general public. It is also important to note that many of the design features advocated by the consumer focus group participants are consistent with the suggestions from the physician participants identified above. Therefore, as the CTFPHC learns to apply these principles to the physician section of the web site, many of the concepts would be transferable to the consumer area of the web site. For example, like the physicians, consumer participants wanted information presented in layers with summaries of the recommendations presented up front and the ability to access more detailed information. This suggests that as consumers want more information, the layers of information available for the physicians and the general public could merge. This ability to access information at different levels of complexity is one of the advantages of electronic publication of research evidence (Bero & Jadad, 1997).

However, there would be challenges in adapting the large body of information that the CTFPHC has for the first levels of information available on the consumer web site. Participants in the consumer groups wanted the information kept simple and written in understandable language. The challenges the CTFPHC could face in developing the content of the consumer area of the web site will be addressed in the following section.

Challenges

Producing Consumer Health Information

Based on the literature, and consumer focus group, key-informant and organizational interview findings, producing information for members of the general public is a significant undertaking both in terms of time and production costs. In addition to computer and web site skills (database programming and HTML coding), the CTFPHC would require individuals with skills in writing health information for consumers, focus group and usability testing, and graphic design to produce consumer health information.

In addition to the above production requirements, there would also be communication strategies and process issues to be addressed. For example, the CTFPHC would have to decide if they are trying to target the information to a particular segment of the population. The challenges and merits of producing targeted information were debates highlighted in the key-informant and organizational interviews. Furthermore, the Task Force would need to address how best it can explain uncertainty and controversy when the evidence is unclear. Both physicians and consumers were comfortable with the notion of uncertainty due to lack of evidence. However, both groups wanted the CTF to document the controversy and explain the issues to help them make decisions. The Task Force would also need to outline a strategy for developing consumer health information; including, for example, establishing a process for expert content review of each topic, as well as consumer testing of the information and its presentation (Coulter et al., 1999).

Finally, a gap exists between some of what consumers want and what the CTFPHC can provide. For example, participants in the consumer focus groups wanted information on how to prevent getting disease in the first place (e.g. through lifestyle change) and many participants were interested in issues where no scientific evidence is available (e.g. herbal therapies).

Evidence is often limited or of poor quality for some of these issues. Also, some topics are not part of the CTFPHC mandate. The gap between consumer needs and evidence-based research was identified in the key-informant and organizational interviews, as well as in the literature (Entwistle et al., 1998)..

The Task Force will need to carefully consider all of these issues as we decide on the feasibility of a consumer information initiative.

Dissemination and Implementation Issues

Throughout this project, it became apparent that the issues of dissemination, uptake and implementation discussed in terms of physician adoption of CPGs in a previous Task Force report (CTFPHC, 1999) are applicable not only to physicians, but also consumers and consumer advocates. Academics and professionals are using different words to explain similar strategies for different segments of the population. For example, the medical literature talks about dissemination of CPGs to physicians to encourage adoption of best practices and the health promotion literature talks about the communication of key messages to consumers to encourage adoption of healthy behaviours. Although the intended outcomes may be different (best practices compared to healthy behaviours), ultimately the goal is to change the behaviour of individuals, either clinicians or consumers. Unfortunately, behaviour change is a complex and difficult process.

Our findings suggest at least two opportunities that the CTFPHC could explore to potentially enhance its provision of clinical prevention information on a web site to the physician and consumer target groups. First, the Task Force could increase its visibility to the intended target groups. Second, the Task Force could consider collaborating with organizations involved with these groups (e.g. professional associations, consumer advocacy groups).

The CTFPHC had credibility with the participants in the physician focus groups because of the evidence-based nature of their recommendations, as well as the long-standing history of the group as a pioneer in this area. It also has a number of features that the consumer focus participants labeled as credible, including non-corporate funding and credible information with identifiable sources. The findings suggest that the CTFPHC credibility would be maintained with physicians through regular updates of the web site. Furthermore, credibility could be enhanced for all target groups if the web site was marketed to increase the visibility of the web site and the Canadian Task Force itself. This was most strongly articulated in the consumer focus groups where they suggested the web site should be marketed through physician offices, health care facilities and the media.

Collaboration with other organizations involved with physicians and consumers may be another means of addressing the challenges of dissemination and implementation. Consumer focus group participants consistently identified consumer advocate organizations such as the Lung Association and the Canadian Cancer Society as places they would go to seek health information. Likewise, the key-informants suggested that collaboration with their organizations may encourage the use of the CTFPHC recommendations as the basis of their consumer health information. However, collaboration with other organizations may not always be feasible as it may lead to compromises in the quality of the information. Entwistle et al. (1998) found that several consumer organizations held views contrary to the research evidence for prostate cancer screening. They were concerned that any potential collaboration would compromise the credibility of the research evidence. Similar concerns were also identified in the organizational interviews.

Working with Prevention

The Canadian Task Force will need to decide if its wants to use the web site strictly as a vehicle to disseminate evidence-based information or if it wants to use the web site as an opportunity to promote and motivate individuals to adopt healthy behaviours. Dissemination of evidence-based information alone could be one part of a national strategy promoting healthy behaviours. Alternatively, there are reasons to believe that the Internet could be used as more than just an information dissemination vehicle, because it allows for interaction between the source and the user (Cassel et al., 1998). For some of the CTFPHC recommendations, the messages to consumers could move beyond the provision of information and try to promote skill development and motivate behaviour change. However, this has not traditionally been the role of the Canadian Task Force, and any potential shift in mandate would have to be carefully considered, and supported with appropriate resources.

Interactivity

Another challenge for the CTFPHC will be to decide how much interactivity to provide on the web site. Both physicians and consumers wanted to be able to enter information such as age, gender, and risk factors, and have the computer generate personalized information from the Canadian Task Force recommendations. This would mean creating a relational database to store and retrieve the CTFPHC information (an initiative currently being discussed with potential academic partners). Some of the physician participants also recommended having the CTFPHC recommendations linked to a computerized office system. However, in many cases the evidence is not available for the topic of interest to users. For example, there is limited data on risk factors for many types of cancer. Dealing with gaps in the database would pose an additional challenge.

These types of databases and interfaces are being developed (Lobach, 1996). In developing patient-specific computer-generated recommendations for physicians, Miller and Frawley (1995) found that there are trade-offs between the specificity and generality of the recommendations. Making the computer-generated guideline more specific could reduce the amount of text the physician is required to read, a feature desired by many of the physician focus group participants. However, sometimes general comments central to the use of the guideline may be helpful to the physician, even if they do not directly apply to the patient in question. It may be simpler to let the physician make some clinical judgments on their own, compared to developing the questions and database queries required to generate that information.

Another interactive feature physician and consumer participants wanted was a place on the web site where they could pose questions for a Task Force member or staff person to answer. Again, this level of responsiveness would pose significant costs, and would require careful consideration.

Summary

This project has given the CTFPHC many insights into the enhancement of our physician web site and a number of issues to consider regarding the development of a consumer-oriented area for the web site. Throughout this process it was apparent that the Task Force has a large body of useful and credible information. High quality information is one of the most expensive components of developing a quality web site. Because it already has high quality information in a synthesized form, the CTFPHC is well on its way to developing a good health information web site. Furthermore, many of the design and format suggestions from the physician focus groups can be incorporated into the current CTFPHC web site. This will create a web site that can provide quick and easy access to the information so physicians can get the answers they need.

However, developing consumer health information in simple and understandable forms would represent a significant initiative for the CTFPHC. Based on the findings from the focus groups and interviews, consumers want basic health information written in understandable language. The Canadian Task Force would need to produce some general health information and re-write the recommendations for the consumer section of the web site. In addition, there would also be challenges in balancing consumer information needs with the available research evidence. Prior to developing these consumer health information materials, some basic decisions need to be made about the (1) intended aims; (2) proposed audience; and (3) the intended context of use. (Coulter et al., 1999; Entwistle, et al., 1998).

Key Issues to Consider When Developing Physician & Consumer Websites

Having considered the feedback gathered directly from physicians and consumers in the focus groups, along with the information from those experienced in providing information to others (consumer advocates and other organizations), two lists have been developed that outline key issues or "principles" to consider when developing websites for 1) physicians; and 2) consumers. These are presented in Appendix 6 (physicians) and Appendix 7 (consumers).

Online Evaluation Survey

A survey has been developed to post to the CTFPHC website. Originally conceived as a survey for physician users, the research team decided to broaden the scope of the survey in order to learn about who is using the website, when, and why. Specifically, the survey asks users to provide:

- Some demographic data (age, geographic location, etc.)
- Information about their computer and internet use
- An evaluation of the site content and usability features (e.g. ease of browsing, searching, etc.)
- An indication of what features they found most and least useful on the site

A draft of this survey is found in Appendix 8. The survey will require pilot testing with a sample of users to evaluate how well it performs in retrieving the required data.

Sample CTFPHC Consumer Information

Background

In the original contract proposal, the research team identified as part of the statement of work the development of sample consumer versions of a subset of currently up-to-date CTF topics. When we first proposed this project, the evidence available came primarily from what other groups similar to CTF (e.g. the UK NHS, and the US AHCPR) were doing to produce consumer versions of their guidelines. This was essentially a "translational" process which took the professional version, condensed and re-worded into lay language, and was entirely paper-based (i.e. booklets and one-page leaflets).

Given that there was not much data on providing patient information in the web medium, or how that might compare to paper versions, we struggled with how to frame the consumer focus groups. Eventually, given that our main concern is to design a usable website, we decided to ask our participants questions related to getting preventive health information on the World Wide Web. This decision led to suggestions from the consumer focus group participants relevant primarily to the website medium, especially in terms of format, layout and design of the information, as well as how to make it appealing and "catchy", and how to market the site.

These data gave us a different perspective on how to develop a process for creating consumer versions of our guidelines for the web. For example, in a dynamic medium such as a website, there is the ability to present the user with options, usually via menus, on which aspect of the guideline they want to see first, and how much of the information they want to see at once. There is also the ability to augment the written information with animated graphics, sounds, etc., and to link information to other related items in virtually unlimited ways. Finally, there is the ability to provide a level of interactivity not possible with a paper brochure. Focus group participants consistently requested the use of these techniques to enhance their information seeking experience.

Another important finding from the consumer focus groups was participants' request for narratives or "personal stories" from other people experiencing prevention-related decision-making. The work on narratives is new and exciting (Greenhalgh, 1999, Enkin & Jadad, 1998) and requires further exploration.

Finally, discussion with other organizations involved in this process tells us that designing patient information, whether for paper-based or electronic forms, is an iterative and interactive process and not as straightforward as initially assumed. We concluded from the evidence gathered that simply following a straight translation process based on the current practice with paper-based information in the web context would not allow us to satisfy the needs expressed by our participants, nor would it do justice to the opportunities provided by the technology.

For the reasons outlined above, the research group felt it premature to develop sample consumer versions until a more thorough exploration of the possibilities for enhancing these products for the website was possible. After discussion of these issues with the scientific authority for the contract, permission was given for the research team to instead focus its efforts on further examining these issues and developing a process for creating consumer versions for the web medium. A discussion of this process follows below, and some sample web pages building on these data are presented.

Development of Sample Consumer Web Pages

Generally speaking, there are 3 components of a potential consumer area for the CTF web site, as outlined in the consumer focus group findings, and supported by the existing literature:

1. Presentation (appeal and attractiveness of information)

2. Organization (layout of the information on the web site)
3. Understandability (translation of the content to consumer versions)

Drawn from our various data sources (focus groups, interviews and the literature review) Appendix 7 outlines the key issues or "principles" that should be considered when developing health information web pages for consumers. In the results section, a thorough analysis of the current "state of the art" as practiced by other evidence-based organizations with consumer initiatives is presented. To summarize, the literature (and other groups) provides scant evidence or guidance for how to communicate this type of information in a web-based medium. Even for paper-based forms, the process as currently used is to: 1) identify key messages, 2) write the text, and 3) evaluate and revise (see Appendix 1). However, these general guidelines are quite practical, even technical, in nature, and do not provide much guidance regarding the writing process, which is iterative and creative in nature.

For the web medium, there is next to nothing available in the literature, and the groups we consulted had not yet fully explored providing online versions of their work. Having said this, the research team did endeavour to develop some examples of consumer web pages, as the initial step in examining how we can evolve a process for converting our existing and future content and providing these in an attractive, usable and well-designed consumer area of the CTF website. These are presented in Appendix 9. Note that these examples are preliminary in nature, and are presented to give a general idea of how the information provided in this study can be applied to a potential website. There are a number of practical and more global issues to consider as this initiative evolves, as discussed in the next section.

Future Directions

Physician Website Initiative

The first step in applying the results of this project, as related to the physician initiative, will be to take the suggestions made by participants and distilled from the literature (outlined in Appendix 6), and make revisions to the current CTFPHC website. While this will not be feasible for all suggestions, there are many straightforward changes that can be made (and in some case already have been made, for example to addition of "printable pages") without engaging extra resources. Other suggestions, such as the development of interactive areas that can provide customized feedback to individual physician queries, will require more thought. If the CTFPHC decides to explore such options, individuals with skills in designing and maintaining relational databases will be required. In the meantime, the development of an interactive CD-ROM as a transitional tool to serve physicians until identified Internet access barriers are addressed should be explored.

Consumer Website Initiative

As described above, the process of creating consumer versions of professionally targeted health information is a complex one, particularly in the web medium. In this project, we have taken some initial steps in identifying the key issues involved in producing such information, and some of the challenges that might be faced should such an initiative move forward. Before this can occur, some global decisions have to be made by the Task Force, including whether the CTFPHC should or could assume the role of a provider of consumer health information. If the answer were yes, resource issues would have to be addressed, as it has become apparent that providing consumer health information is a time-consuming and expensive process. The implications for the CTFPHC's future funding are significant.

At a practical level, a next step in a consumer initiative would involve further developing some sample web pages, incorporating more content and design features (e.g. interactivity, graphics, etc.). Following this, several iterations would be required to evaluate and enhance these products. As a leading authority in this area writes:

> *Focus groups are great for getting information about users' current concerns and areas where they would like help, but they will rarely teach you how to reinvent the fundamental way you do business. Listening carefully to customers will often reveal*

> *frustrations that can turn into opportunities for improvement, but once you have an idea for an improvement, you must create a prototype design and try it out with users in a usability test to see whether it really works for them…The point is that market research forms the starting point but has to be supplemented with usability engineering if you want a design that works when people try to use it. (Nielsen, 1997).*

Thus further testing with groups of users, as well as with individuals "walking-through" the site in a controlled setting, would be required. This would be proposed as a follow-up study, and funding opportunities will be explored.

One obvious advantage to such an initiative, evident in the literature and echoed by our consumer advocate interviewees, is that the <u>production</u> of evidence-based information represents the majority of the cost involved in the overall process of synthesizing and transferring research evidence to end users. Consumer advocates stressed the fact that the CTFPHC's high quality information would be very valuable to them in their work to educate the public about prevention issues. It may be feasible to explore how the CTFPHC could collaborate with such groups to link our production process to their established and well-funded dissemination processes. Of course, as cautioned by one of our organizational interviewees, there are challenges to this type of collaboration, especially for evidence-based groups, whose reliance on available published research evidence often leads to gaps in the information that consumers want, and frustration.

Dissemination Plan

The current report, and/or background information therein, will be disseminated as follows:

1. a summary of findings from the different cohorts (e.g. physician and consumer focus gorup participants) was sent to each participant from that cohort.
2. the report will be developed into an academic manuscript suitable for publication in a peer-reviewed journal;
3. the evolved processes will be presented at appropriate health care meetings or conferences, such as the North American Primary Care Research Group (NAPCRG) meetings, or at the "Cutting Edge of Family Practice" annual family medicine scientific assembly. In addition, results will be discussed at an upcoming Canadian Task Force meeting, and possibly to such evidence-based medicine groups as HealNet, etc.

4. the approaches decided upon will be shared with the United States Preventive Services Task Force (who are already using our website as a model) to explore their interest in collaboration and cross-linking our websites.
5. relevant background information will be posted to the Canadian Task Force world wide website.

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Appendix 1 - Guidelines for Developing Consumer Health Information Materials*

1. Use short sentences, presenting a single idea.
2. Use common words. Avoid words with multiple syllables and technical terms.
3. Write in the active voice.
4. Write in second person, not third person.
5. Determine key messages; these messages should contain the most important information and address the patients' practical concerns. Avoid overwhelming the patient with too much detail.
6. Put the most important information first or last.
7. Organize the information with headings.
8. Summarize and review the key messages.
9. Balance page with white space and text.
10. Select a readable font size (12 or larger, with special considerations for elderly audiences) and use a serif typestyle such as Times New Roman.
11. Don't use ALL CAPS or too much underlining and italics.
12. Text should be left justified.
13. Use consistent formats.
14. Use appropriate illustrations and pictures, but don't be excessive.
15. Work with an experienced graphic designer.
16. Use positive sentences most of the time. Use negative sentences to emphasize avoiding negative action.
17. Write in a conversational style.
18. Use direct questions.
19. Check material for readability and revise as necessary.
20. Pilot test the materials with members of the target audience and revise as necessary.

*These guidelines are taken from the following articles: Baker, 1991; Kripalani, 1995; Meade & Smith, 1991.

Appendix 2 - Physician Focus Group Interview Guide

1) Tell us your name, where you practice medicine, and if you wish you can also share with the group your funniest, weirdest or strangest experience using a computer.
2) Describe what the Internet means to you in 10 words or less.
3) Okay, now we are going to take a step back from the Internet and computer technology for a moment. I want you to picture yourself in your role as a physician. Think of the last time that you needed information on prevention issues. Can you please share this example with the group.
   a) You have described a number of situations where you have needed information – *briefly summarize what was said* –Are there any other circumstances where you find yourself looking for information on preventive clinical practice guidelines?
   b) In these situations, what do you want to know? What kind of information are you looking for?
4) Now we are going to start looking at how you would like this information presented on a website. It was mentioned earlier in the discussion that ---<u>select information type mentioned by participants</u>--- How do you want that --<u>information type</u>-- presented? **Repeat as needed.**
5) What kinds of things make finding this information easy? [FACILITATORS]
6) What kinds of things making finding this information more difficult? [BARRIERS]
7) POSSIBLE PROBES

   In our last focus group, there was a discussion about whether the guidelines should be published in book form or the website, or some other form? Do you have any thoughts on how the guidelines should be published?

   Participants in the last focus group commented a great deal about how they want to be able to print a paper copy of the information on the web site. What are your feelings about this statement?
8) In our last focus group we had a big discussion about patient information and whether or not there should be separate physician information and patient information. What are your thoughts?
9) Our purpose today was to explore how a website could be organized to be useful for physicians wanting information about evidence-based clinical practice guidelines on prevention issues, trying to look at what type of information you need and how you would like to access this information on a website. Have we missed anything?
10) What to you has been the most important topic we have discussed today?
11) Suppose you were in change of developing a website of evidence-based guidelines on prevention. What would you want to do?

Appendix 3 - Consumer Focus Group Interview Guide

1) Tell us your name and share with the group your funniest, weirdest or strangest experience using a computer

2) In recruiting participants for this focus group, we asked that each of you be familiar with the world-wide-web. Now, don't worry, we weren't looking for web experts! We wanted to talk to people who had spent some time searching for information on the world-wide-web. Before we start talking specifically about the information we would have on our website, I would like to hear from you about web site features you liked on sites you have visited. What features did you dislike?

Things to probe:

- Use of pictures and graphical information?
- Format/ presentation style?

3) Okay, before we talk about designing a web site specifically for the Task Force, I want to take some time to talk about your needs for information about prevention. You have seen a list identifying the kind of preventive health information that the Task Force has. I want you to think about a time when you wanted to get this type of health information. Maybe you or someone you know wanted to get some information on preventing disease or detecting disease early. [Pause]

4) I would like some of you to share your example with the group. Does anyone have an experience they would like to share?

5) You have described a number of situations where you have wanted preventive health information. **What kinds of things do you want to know?** (*if necessary, probe with specific examples given by group*)

Things to probe:

- What is the most important information?
- How much detail?
- How do you want various risks presented?
- How do you want uncertainties explained?
- Tone – probe what they mean if mentioned

If necessary, we can use these questions to get more information about "what participants want to know.

a) Okay, let's take a couple of examples where there is really good information about what works. For example, there is good evidence that blood pressure should be checked in adults to screen for coronary heart disease and women should have regular pap smears to screen for cervical cancer. What kind of information do you want to know in these types of situations?

b) Now, let's look at some issues where there are a number of questions and the evidence is really unclear. For example, there are a number of questions around the use of hormone replacement therapy in women and how it affects a woman's risk of breast cancer and the potential protective effects for cardiovascular disease and osteoporosis. And for men, there are number of questions around screening for prostate cancer. In cases like these where there are a number of questions and the evidence is unclear, what do you want to know then?

c) We have talked about cases where there is really good information about what works and cases where the information is not clear cut. What the Canadian Task Force on Preventive Health Care does is grade this evidence. There are 3 basic types of evidence: (1) really good evidence to do something; (2) good evidence not to do something, or it may be harmful; and (3) cases where the evidence is unclear. Is knowing the grade of evidence important to you?

6) Thinking about all the information you have identified that you want to know, what ideas or suggestions do you have for us in designing a useful web site with this information?

7) How do you foresee using this information?

8) What sources of health information do you trust?

a) If you are looking for information in printed materials such as pamphlets and magazines to get your health information, what sources of information do you trust?

Things to probe:

- What is it about these sources that make you trust them?
- Is there anything else that affects your trust?
- You have talked about web site sources and print sources that you trust, what about personal sources. What people do you trust as sources of health information?

9) Is there anything else you can tell us that would help us prepare information so that we can better provide you with easy access to understandable, appropriate, and useful health information?

Appendix 4 - Key Informant Interview Guide

Primary questions:

1) Could you tell me a little bit about your job, and how you are involved in giving health information to members of the general public.

2) Based on your experiences, what advice can you give us as we look into preparing a web site with information for members of the general public on the Task Force's recommendations?

    a) What kind of information do you think members of the general public want to know about clinical prevention issues such as screening, immunization and lifestyle counseling?

    b) What kind of information do you think members of the general public need to know about these clinical prevention issues?

    Things to probe:
    - *What is the most important information?*
    - *How much detail?*
    - *How should uncertainties be explained?*
    - *How should risks be presented?*

    c) Do you have any specific ideas or suggestions for us in designing a useful web site for consumers with this type of information?

    Things to probe:

    - *Tone*
    - *Use of graphics*
    - *Format and presentation style*
    - *Interactivity*

    d) The Task Force grades the medical evidence into 3 general categories: (1) good evidence to do something (e.g. mammography for women 50-69); (2) good evidence not to do something (e.g. chest x-ray for lung cancer); and (3) cases where the evidence is unclear (screening for gestational diabetes mellitus). Do you think knowing the grade of evidence is important to consumers? Would it be important to you?

Secondary questions:

3) Do you think the recommendations from the Canadian Task Force on Preventive Health Care would be relevant to your work? Why or Why not?

If yes . . .

- What kind of information would be most useful to you?
- How could you see using the CTF web site in your work?
- You gave a number of suggestions for developing a web site for consumers, what kinds of things would you like to see on a web site like this to help you with your work?

Things to probe:

- *Use of graphics*
- *Format and presentation style*
- *Interactivity*
- *What is the most important information?*
- *How much detail?*
- *How should uncertainties be explained?*

If no . . .

- Is there anything we can do to make this information more relevant to your work?

Appendix 5 - Consumer Participant Selection Criteria

Each participant must be:

- interested in participating (question 1);
- between the ages of 35 and 65 (question 2);
- have experience “surfing” the world wide web (question 3);
- browse the Internet 2-3 times a month or more (question 4).*

Are you interested in discussing in a group setting the kind of information on preventive health care you would like to be included on a web site?	___**Yes**	___No
Are you between 35 and 65 years of age?	___**Yes**	___No
Do you have experience “surfing” the world wide web?	___**Yes**	___No
How often do you browse or look for information on the Internet?	a) More than once a week b) Once a week c) 2-3 times a month d) Once a month e) Every 6 months	

Eligible participant:

- answers “**Yes**” to questions 1, 2, and 3 and answers **(a), (b),** or **(c)** to question 4.

Ineligible participant:

- answers “No” to question 1 **OR**
- answers “No” to question 2 **OR**
- answers “No” to question 3 **OR**

Appendix 6 - Key Issues to Consider when Developing Physician Website

The following is a brief summary of the main suggestions provided by physicians during the focus groups. All of these suggestions were generally agreed to by participants, and can be viewed as "principles" to guide the refinement of the physician area of the CTF website. Those points that came out especially strongly are indicated by ✓✓.

Web Site Content

- General Information to Include:
    - ✓ Names and contact information for Canadian Task Force members
    - ✓✓ Funding Agencies
    - ✓ Methodology
    - ✓ Explanations of grades of recommendations
    - ✓ Names of authors
    - ✓ List of reviews in progress

- Specific Information to Include for Recommendations
    - ✓ Frequency of screening tests
    - ✓ Number needed to treat
    - ✓✓ Summary of evidence
    - ✓✓ List of references (and access to full references or abstracts, if possible)
    - ✓ Full text of review
    - ✓✓ Explanations when the evidence is unclear or conflicts with other guidelines
    - ✓✓ Date of recommendation
    - ✓✓ Grade of recommendation
    - ✓ Suggested counseling strategies

- Additional Helpful Information to Include
    - ✓✓ Patient information (to hand-out to patients and for them to bring in to physician)
    - ✓ Links to related CTF guidelines within web site
    - ✓ Guidelines of other organizations on same topic

Web Site Design and Format Issues

- Easy Web Site Navigation
    - ✓✓ Quick access to summary of recommendations with internal links to more detailed information (see above)
    - ✓ Easy home page access
    - ✓✓ Date of last update
    - ✓ New information section

- Easy Access to Information
    - ✓✓ Index system (physicians classify information by disease, organ system, screening test, age, gender, and family history)
    - ✓ Internal search function

- Simple Web Site Design (✓✓) (to ensure speed of access and minimal waiting for upload)
  - ✓✓ Use mainly text-based information
  - ✓ Use minimal graphics
  - ✓✓ Create “printable” pages

- Interactive Components
  - ✓ Provide opportunity to enter patient information to generate a list of relevant information
  - ✓✓ Layer the information to offer the user choice
  - ✓ Allow user to ask questions and receive answers from CTFPHC member/staff or provide private discussion section for physicians

- Links to other Web Sites
  - ✓ Provide links to specific web sites (other guideline sites especially)
  - ✓ Identify Canadian web sites

Appendix 7 - Key Issues to Consider when Developing Consumers Website

The following is a brief summary of the main suggestions provided by consumers during the focus groups. All of these suggestions were generally agreed to by participants, and can be viewed as "principles" to guide development of a potential consumer area for the CTF website. Those points that came out especially strongly are indicated by ✓✓.

Web Site Content

- Keep it simple (✓✓)
- Use laymen’s terms (✓✓)
- Provide easy access to definitions of medical terms

- General Information to Include:
  - ✓ Who funds the Task Force?
  - ✓ Introduction and explanation of information found on web site
  - ✓ Advise people that they should consult their own doctors

- Specific Information to Include for Recommendations
  - ✓ Frequency and explanation of screening tests
  - ✓ List of references
  - ✓ When the evidence is unclear - tell people why, and what other factors they should consider and discuss with their doctor
  - ✓ Personal stories from patients/consumers with similar experiences
  - ✓ Date that the Task Force recommendation was made
  - ✓ Grade of recommendation with explanation of what grade means

- Do **Not** Include:
  - ✓✓ Corporate advertising

Web Site Design and Format Issues

- Easy Web Site Navigation
  - ✓✓ Quick access to summary of recommendations
  - ✓ Easy home page access
  - ✓ Date of last update
  - ✓ New information section

- Easy Access to Information
  - ✓✓ Index system
  - ✓ Alphabetical listing of topics
  - ✓ Internal search function
  - ✓ Access to information by age (✓✓), gender, and family history

- Appealing Web Site Design (✓✓)
    - ✓ Visually appealing
    - ✓ Use graphics as substitute for text
    - ✓ Use colour
    - ✓ Use creative and attention grabbing text

- Interactive Components
    - ✓✓ Layer the information to offer the user choice of how much to see at once
    - ✓ Allow user to enter personal information to generate a list of relevant information
    - ✓ Allow user to ask questions and receive answers from CTFPHC member or staff

- Links to other Web Sites
    - ✓ Provide links to specific web sites with relevant and trustworthy information
    - ✓ Identify Canadian web sites
    - ✓ Provide disclaimer when leaving CTFPHC site

Market Web Site

- Posters and pamphlets in doctor’s offices and health care facilities
- Media advertising on TV and radio

Appendix 8 - DRAFT Website Evaluation Survey

Thank you for taking the time to complete this survey. The information you provide will help us determine, in general terms, who our visitors are, how and why they are using this site, as well as providing an opportunity for you to tell us what you think of our site. This will allow us to keep improving our site, to better serve our users. Please indicate your responses by clicking in the box next to your answer.

---

1. User Information:

a. Please select the option that best describes you:

Primary Care Physician
Primary Care Nurse
Specialist Physician - Please specify: ____________________________
Other Clinician or Health Care Professional - Please specify: _______________
Health Care Planner or Policy Maker
Patient/Health Care Consumer

b. What is your age?

Under 18
19-25
26-40
41-65
Over 65

c. What is your current geographic location:

Alberta
British Columbia
Manitoba
New Brunswick
Newfoundland
Nova Scotia
NWT
Ontario
PEI
Québec
Saskatchewan
Yukon
Nunavut
United States of America
Other __________________

d. How frequently do you use a computer?

Daily
Weekly
Less than once a month

e. How many hours per week do you spend on the internet?

less than 5 hours
5-10 hours
10-20 hours
More than 20 hours

f. Where do you spend the majority of your online time:

work
home

2. Use of this Site:

a. Why did you visit this site today?

to find a specific recommendation, preventive action, or disease/condition
to browse Task Force recommendations, in general
to see what was new on the site
just curious
It was an accident

b. Will you visit this site again?

Yes No

Please comment on why or why not.

____

____

____

c. Which area did you find most helpful? ____________________________________

d. How did you learn about this site?

Link from another WWW site. Please specify ___________________________
Read about it (e.g. in a journal or newsletter).
Please specify; __________________________
Word of mouth
Search engine i.e. Yahoo
Other. Please specify: _______________________________

3. Evaluation of Site Content & Usability:

a. Overall, how would you rate this site?

Excellent
Above Average
Average
Below Average
Poor

b. How credible was the information on this site?

Very credible
Above average
Average
Below average
Not credible
Can’t evaluate

c. Overall, how easy was it to use this site?

Very easy
Easy
Average
Difficult
Very difficult

d. How easy was it to search this site?

Very easy
Easy
Average
Difficult
Very difficult

What changes, if any, would make it easier to search this site?

4. General Comments:

a. What is the one thing you would change about the site?

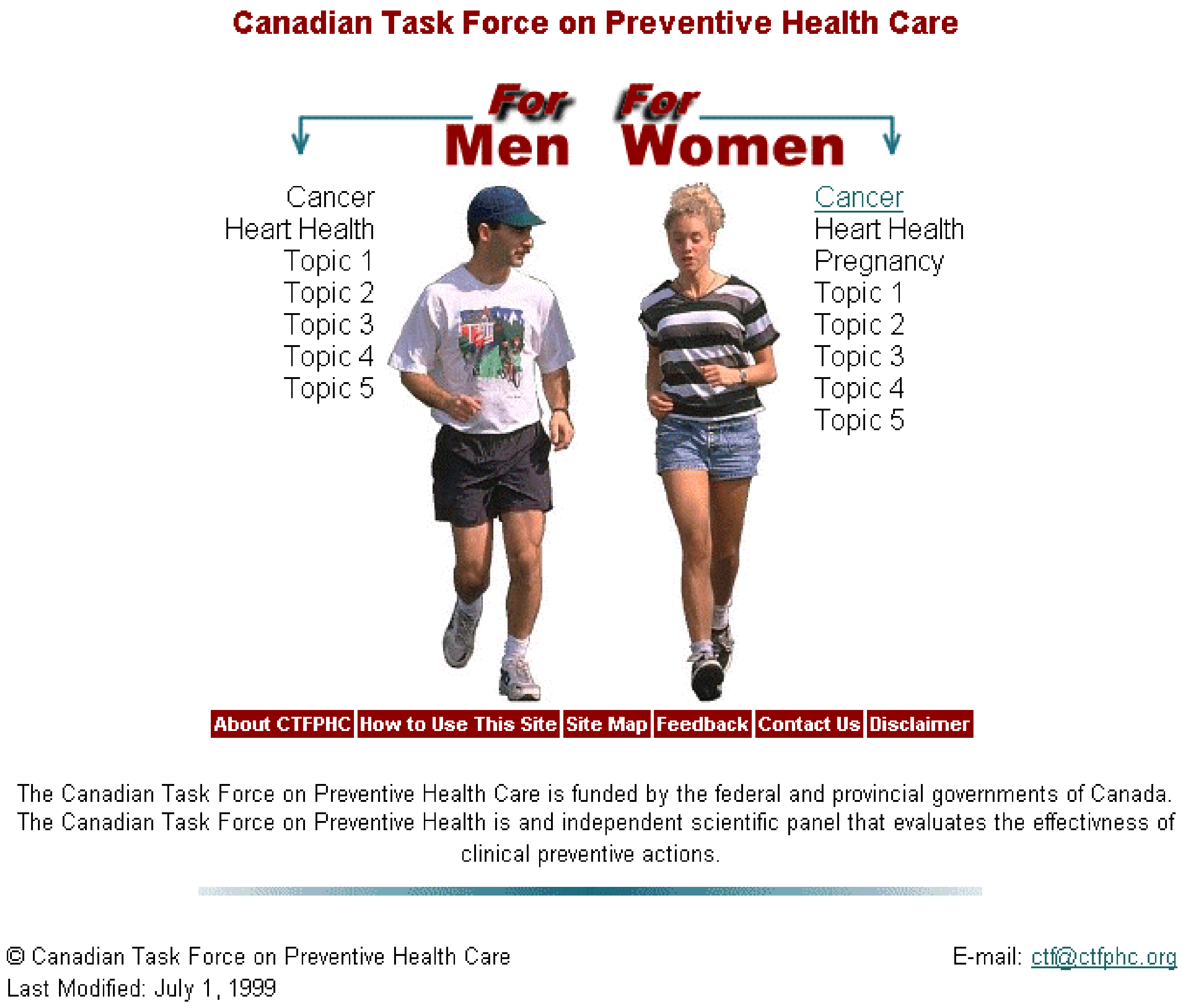
b. What did you like best about the site?

c. Is there anything else that will help us improve the content or usability of this site?

Appendix 9 - Sample Consumer Web Pages

Home Page Design

- Text is clearly readable (good size font, background colour and white spacing between)
- Images that relate to subjects (lay persons) doing activity relating to health promotion and disease prevention (e.g. jogging)
- Easy to read menus (appropriate wording for consumer vocabulary)
- Menus organized by gender as per request from consumer focus groups
- Clearly visible links
- Disclaimer added to the bottom of the page
- Categories such as "Heart Health" use words oriented to consumers (as opposed to Cardiovascular Disease)



Canadian Task Force on Preventive Health Care

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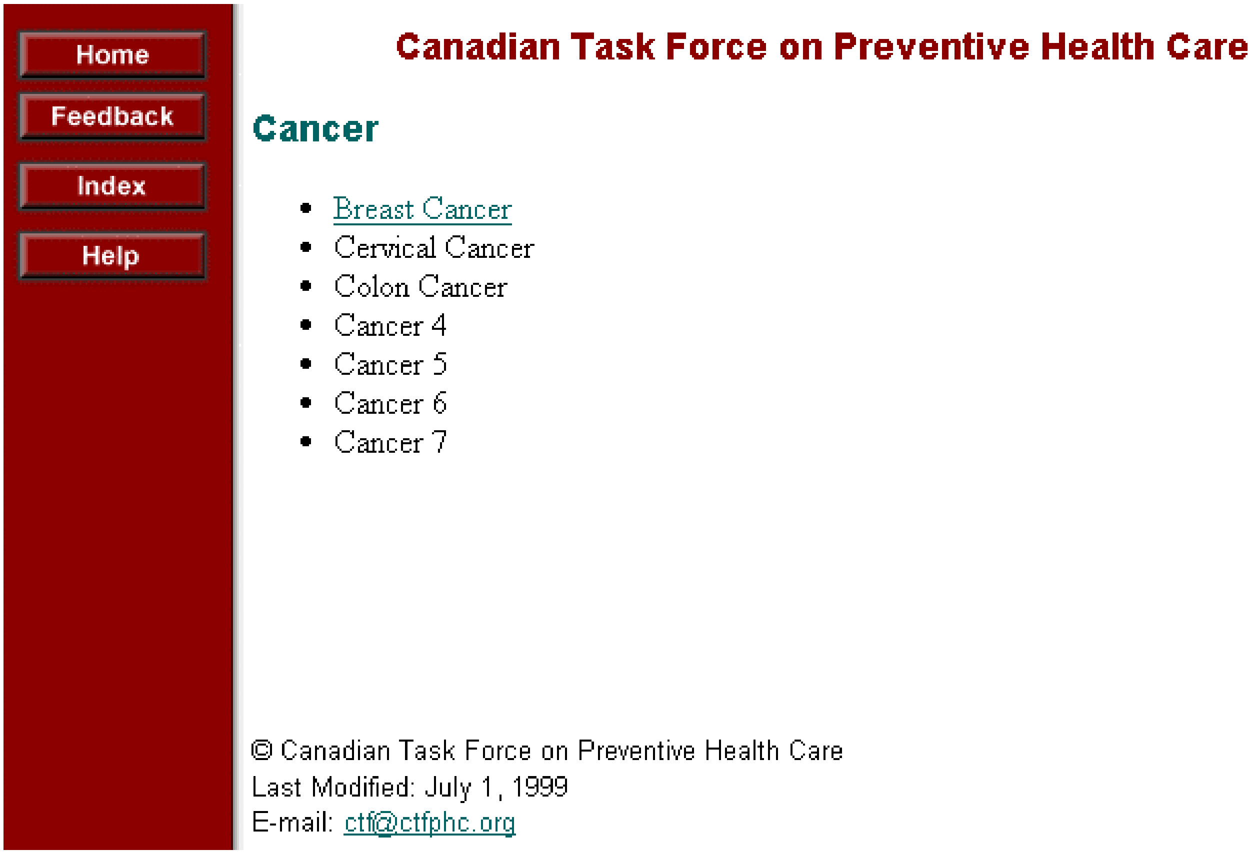
Main Category and Sub-Category Web Page Design

- Categories use words familiar to consumers "Cancer" and "Breast Cancer" as opposed to medical terms
- Information on how to detect and prevent a disease was requested by consumers, hence there is a section on breast self-examination
- Consistent use of side bar to help navigation
- Layering of subject categories
- Title at the top makes the information clearly labelled as to its reliable source
- Clickable links to go back to main category
- Text is clearly readable (good size font, background colour and white spacing between)
- Help information is easily accessible on sidebar
- Each page has a date of last update and email contact information
- The index on the side bar would need to be developed using words familiar to the consumers. This is a major undertaking as there is no existing consumer oriented health vocobulary for indexing, as opposed to existing vocabularies such as MeSH used in Medline for indexing clinical literature.



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Cancer

- Breast Cancer
- Cervical Cancer
- Colon Cancer
- Cancer 4
- Cancer 5
- Cancer 6
- Cancer 7

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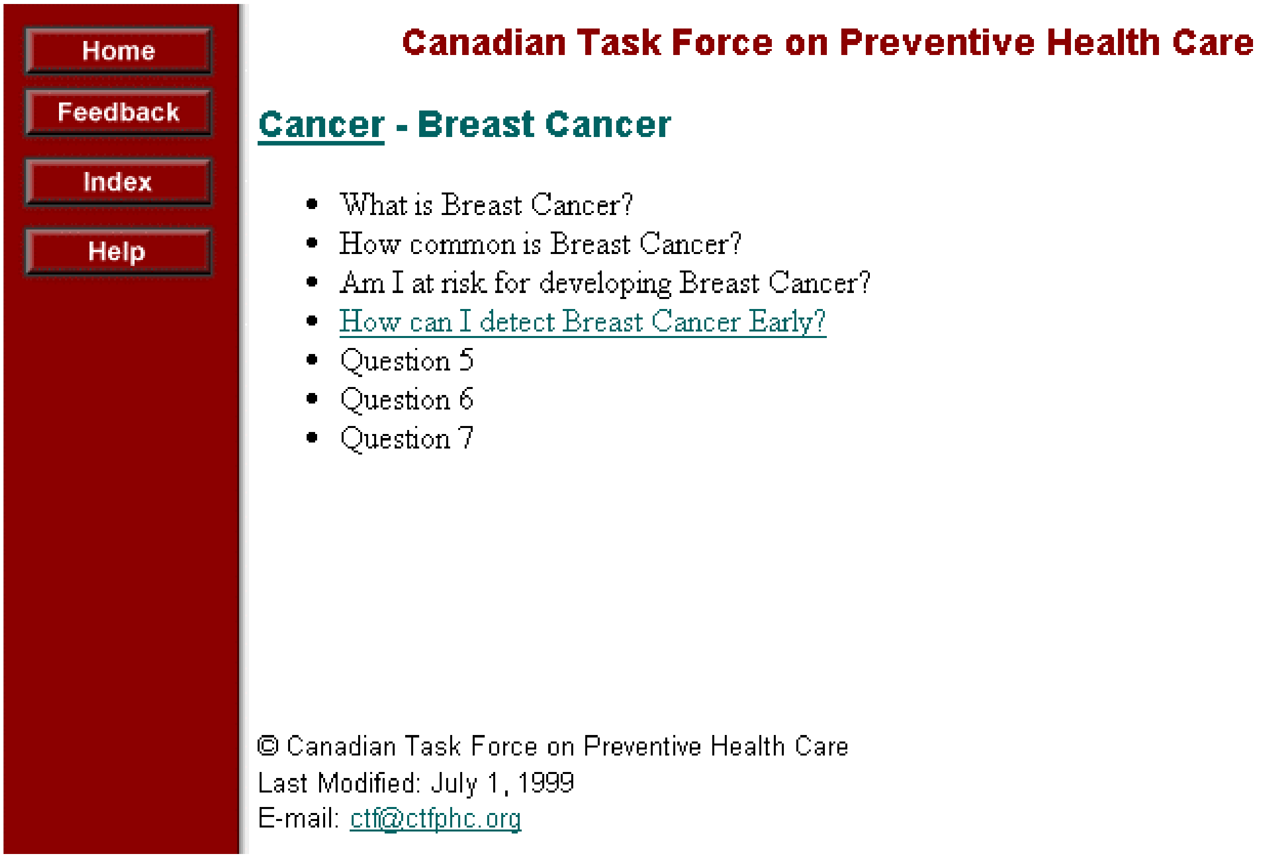

Canadian Task Force on Preventive Health Care

Cancer - Breast Cancer

- What is Breast Cancer?
- How common is Breast Cancer?
- Am I at risk for developing Breast Cancer?
- How can I detect Breast Cancer Early?
- Question 5
- Question 6
- Question 7

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Cancer - Breast Cancer - How can I detect Breast Cancer Early?

- Breast Self-Examination
- Mammography and Examination by Physician

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Appendix 10- Annotations of Key Papers

Physician Literature

Hales, Gadd & Lobach (1997)
Computerization of clinical practice guidelines (CPGs) has been proposed as one solution to enhance the use of guidelines in influencing standard clinical care. Clinicians who best understand the content of CPGs are typically ill equipped to convert textual guidelines into a computer accessible format. The potential of knowledge acquisition tools to assist in this process has been documented in the literature. The ultimate goal is to develop a tool (e.g., the Guideline Entry Wizard) to convert text-based CPGs to a relational database, providing an interactive, guideline-based decision support on the Internet.

Hayward, Guyatt, Moore, McKibbon & Carter (1997)
These authors conducted a study of Canadian physicians to understand their information preferences, needs and uses (note: of the over 3000 Canadian physicians surveyed, about one third were primary care physicians). Informal discussions had the greatest impact on clinical decision-making.. More formal training and reading were also influential. The sources reported as having the least impact on clinical decision-making were: pocket notes, clinical practice guidelines, brief updates, original research articles, position papers, computerized literature searches, and insurance plan policies. These results are consistent with the findings from similar studies of physicians' information source preferences.

Verhoeven, Boerma & Meyboom-de Jong (1995)
Analysis of the use of information sources by family physicians is important for both practical and theoretical reasons. First, analysis of the ways in which family physicians handle information may point to opportunities for improvement. Second, such efforts may lead to improvements in the methodology of literature research in general. Accessibility appears to be an important factor in influencing family physicians’ use of information. In fact, accessibility is more important than factors related to quality (i.e. reliability and completeness of the information). Accessibility is facilitated by a strong index system, which makes the information easier to find and actually increases its use. Print sources with inadequate indexes are rarely used.

Consumer Literature

Bero & Jadad (1997)
Systematic reviews can be a very useful decision-making tool for both consumers and policymakers. However, little evidence of their direct impact on the decisions made by consumers and policymakers is available. Strategies for optimizing the use of systematic reviews include increasing the awareness and identification of reviews, learning to critically evaluate the findings of reviews, and overcoming barriers to the incorporation of reviews into the decision-making process. One of the advantages of electronic publication of research evidence is that there are fewer barriers to accessing information at different levels of complexity. The inclusion of consumers and policymakers in the design, conduct, and reporting of systematic reviews can help to produce reviews that are relevant and understandable to target audiences.

Strategies for increasing the use of systematic reviews should be evaluated for their usefulness in the decision-making process.

Cassell, Jackson & Cheuvront (1998)
This article offers a theoretical rationale for using the Internet to conduct persuasive public health interventions. The authors propose that the Internet 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. They suggest that the Internet has greater ability than other mass media to apply principles of health behaviour theories.

Coulter, Entwistle & Gilbert (1999)
Using focus groups with patients having experience with specific health problems, patient information needs during course of illness and treatment were identified. Patients want honest (if evidence is unclear, say so) and accurate information on a full range of treatment options and side effects. The authors suggested the information should be based on systematic reviews. Patients don't like educational materials to have a patronizing tone. They want educational information to promote a participatory approach to shared decision making. This article outlines a process for developing patient educational materials that highlights involving patients and clinical experts throughout the process. Focus group participants did not identify clear preferences for the media used to communicate the information. Participants were more concerned with the content of the information.

Enkin & Jadad (1998)
Anecdotes are powerful tools that aid in decision making, yet despite their power and influence, they are sometimes misused or undervalued. Ignoring or underestimating their role in health care decisions may hinder communication between decision-makers and impair their uptake of research evidence. Some argue that the application of research evidence into clinical practice can be facilitated by using narratives as the vehicle to deliver research results not only to consumers, but also to clinicians, policy makers and politicians. Anecdotes should not be considered as a replacement for, but as a compliment to formal research evidence. The importance of anecdotes needs to be acknowledged, studied and utilized if evidence-based health care is to meet its full potential.

Entwistle, Watt, Davis, Dickson, Pickard & Rosser (1998)
This paper identifies a number of issues that arose during the development of information materials for health professionals and patients from evidence-based research for the purpose of helping patients make informed decisions. Paper presents the specific process and challenges in developing information materials in four different topic areas - one of which was prevention oriented (prostate cancer screening). It is important to note that the researchers received topic specific input from both health professionals and patients. The following issues were identified:

Issues that arose:
- how do you help patients make informed choices when health professionals are reluctant to support certain options?
- local situations may make it difficult to implement evidence-informed patient choice

- writing to support patient involvement in decisions is a special skill
- one leaflet cannot meet all information needs
- communication media may need to be carefully selected for certain patient groups
- people may need to be encouraged to ask for information and discuss their problem.
- **decisions about screening are more complex than decisions about treatment**
- the importance of being aware of the context and recognizing "where people are at"
- **challenges of informing without actively stimulating interest**
- collaboration with a consumer organization may not always be feasible

Entwistle, Sheldon, Sowden & Watt (1996)
Describes the philosophical and theoretical issues around the provision of consumer health information to support consumer involvement in decision making. The authors discuss dimensions of quality health information from a consequentialist perspective. Within the consequentialist perspective, value is given to health and well-being. Therefore, if the provision of health information has a beneficial effect on the health and well-being of consumers, it is seen as quality health information. The article lists a number of patient information quality checklists but cautions readers about their hidden value judgements and assumptions. Article then discusses how decisions are reached (professional and consumer contributions to decision-making and approaches to decision making). Authors then discuss the various dimensions of quality including (1) relevance - how much information should consumers be told; (2) accuracy - including appropriate information for the individual; (3) accessibility; (4) comprehensibility; (5) usability and equity, and (6) acceptability.

Farquhar, Formann, Flora & Maccoby (1991)
This chapter outlines the multiple methods of communication available to promote healthy behaviours. Face to face communication methods, points of purchase communication methods, and mass media communication methods are presented and examples are given. The authors believe multiple communication strategies are required to achieve lasting behaviour change. Social marketing as a component of a comprehensive program provides useful techniques for planning and implementation of the campaign. Social marketing emphasizes audience analysis, segmentation, message pre-testing, and ongoing evaluation. The authors argue that the problems of implementing these comprehensive communication programs are much less than the costs of not implementing them.

Foltz & Sullivan (1996)
In addition to assessing reading levels, Foltz and Sullivan (1996) studied learning presentation preference and desire for information among 63 cancer patients, most of whom were African American. Seventy-seven percent of the participants preferred personal interactive learning. Reading materials were a useful secondary source of information. However, 90% of the participants wanted all available information.

Jadad & Gagliardi (1998)
The Internet and the proliferation of information available have triggered an information revolution of unprecedented magnitude. In spite of the wealth and accessibility of information provided by the Internet, this may also result in many potentially harmful effects on both consumers and health professionals who do not use it appropriately. Several instruments have

been developed to assess the quality of health related web sites, citing criteria including: content, design and aesthetics of site, disclosure of authors, sponsors, developers, currency of information, authority of source, ease of use, and accessibility and availability. Some authors have suggested that the next step is to develop a simple set of criteria that the general public can understand. However, it is unclear whether or not the instruments to evaluate health information on the Internet should exist in the first place, whether they measure what they claim to measure, or whether they lead to more good than harm. It is questionable whether users would even notice evaluations of the information.

Meade & Smith (1991)
This is an article on the limitations of readability, but it encourages creators of patient information materials to consider patient motivations prior to development of material.

Michielutte, Bahnson, Dignan & Schroeder (1992)
Research indicates that the complexity of language utilised in the available health care information precludes its accessibility to a large proportion of the population in greatest need of health information. This study shows that comprehension of health information among poor readers was greater in a brochure with illustrations and narrative text than it was for a brochure with bullet type text and no illustrations. Narratives create an educational experience that is memorable, grounded in experience and provide an excellent educational tool for patients. These results suggest that the use of illustrations and appealing text style can make health education literature more accessible to high-risk populations, while maintaining the interest of individuals at higher levels of reading ability.

Patterson & Teale (1997)
Simple written information was shown to increase recall of diagnosis and increase patient satisfaction. Authors suggest that patients, particularly the elderly, should be given written information following their diagnosis.

Silberg (1997)
More often than not, the Internet presents medical information in a conversational fashion rather than as a tool for effective health care communication and decision making. A core standard needs be instituted allowing consumers and professionals alike to reasonably judge the credibility and reliability of the material and to make informed decisions about how to apply the information in the real world. To achieve these goals, electronic sources should include information outlining authorship, attribution (e.g., content source), disclosure, (e.g., web site ownership), and currency. The Internet should facilitate, not serve as a barrier to, care of high quality.

Tang (1998)
Article is about generating patient specific materials following the patient visit with the physician. Highlights some key points of what patients like to see - developed an algorithm for "Patient." Uses focus groups, questions for preliminary focus groups actually used samples for people to comment on. We should probably consider this for our focus groups. Endorsement of

the information by their physician was important for the participants in this study - should we be considering this point? How may this affect what we do with our physician focus groups?

Wyatt (1997)

The ease with which information can be disseminated via the Internet makes it difficult for readers to distinguish between genuine insight and deliberate invention, thus requiring proposals for improving the accountability of medical information on the Internet. In evaluating a web site, it is important to consider the content and structure, function, and impact of the site. Two key issues common to many evaluation studies include choosing appropriate subjects (e.g., studies of information technology often employ enthusiasts for the technology in question) and making reliable, valid measurements. The effect of information dissemination via the World Wide Web on clinical practice must be demonstrated via published trials before there is large-scale expenditure on web sites.