

**E-Learning to support health literacy,  
health promotion and disease management  
in community settings**

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## **EXECUTIVE SUMMARY**

### **Project background**

Demographic and technical forces are changing the way Canadians learn about their health. These societal forces require clinicians and educators to change the way they provide patient education. Researchers from Centennial College and George Brown College, partnered with the Keewatinook Okimakanak Research Institute (KORI) in Northern Ontario, St. Christopher House (SCH), Toronto, and a family health team from the Centre for Effective Practice, Toronto, and a cancer clinic to examine the use of innovative web-based health information sites.

Three models of website health information were introduced at the partner sites: Patients from the Family Health team and clinic were ‘prescribed’ tailored health information on PEPTalk, a site that houses vetted health information, by their doctor or nurse. Community participants from KORl and SCH were directed to PEPTalk and to a locally developed website to obtain health information by the project team and community researchers. A descriptive study using surveys, interviews and web log data was conducted to determine the impact of these online health literacy resources on community members’ website use, satisfaction and health literacy and health behaviour. The impact of the emerging health information intermediary role on community leaders and physicians’ practice and workload was also explored. The study was funded by the Canadian Council on Learning.

### **Results**

One hundred and twenty-seven persons participated in the study. Eighteen clinicians and SCH community members participated in the initial needs assessment activities to determine how best to implement the health information websites. Sixty-five First Nations community members from the Keewatinook Okimakanak (KO) community, 29 family health team/clinic patients and eight community members from SCH used the KO and/or PEPTalk websites to access text and video-based health information and completed satisfaction and health knowledge

surveys. Interviews were conducted with all (n = 7) project clinicians and community personnel to gain insight into the impact of health website referrals on their workload and health/knowledge outcomes.

One of the project objectives was to examine patient and clinician website usage. Of the 87 patients who were referred by physicians to PEPTalk, just 29 (33%) logged onto the website. Interview results with physicians suggest that using PEPTalk requires the patient to take an active role in their health education, it is more demanding than simply reading a pamphlet. Four patients reported technical problems with the site which may have also contributed to the results. Community members at SCH and the KO communities used a different approach where participants were given a demonstration or one-to-one assistance to get onto the site. Individual accounts were not created for these users; this approach worked well, indicating the value in providing ongoing website user support.

Thirty-four participants completed the Perceived Health Web Site Usability (PHWSUQ) questionnaire, a validated, reliable website satisfaction survey, in relation to PEPTalk. The mean score for the survey for patients was 40.4 (SD 4.7) out of a possible 50 and scores ranged from 33 to 48, indicating that most patients were very satisfied with PEPTalk. The mean score for KO PEPTalk users was 38.4 (SD 4.5) and scores ranged from 32 to 45, indicating a moderately satisfactory experience. Most participants generally found the information provided was useful, relevant and had improved their knowledge about health. While results for most survey items were similar, they differed significantly for the two groups in regard to three items. Satisfaction scores were lower for the KO participants for these items: *“The overall appearance of the site makes it easy to use”*, *“Overall I found it easy to learn to use this website,”* and, *“This information on the website will help me maintain better health habits.”* These results have implications for improving the site design and navigation process. Further, feedback from the KO participants suggests that health information websites should be a part of a broader umbrella of educational resources; community members indicated that they favour a more interactive approach to health education. The mean score for the PHWSUQ for the SCH personal support workers was 48 out of 50. That very high satisfaction score reflects the keen interest this group

has in having access to reliable health information for their professional development to support client care.

Patient self-efficacy and health literacy regarding disease management and health behaviour change were measured using items on the PHWSUQ and open-ended survey items. All groups reported they had gained knowledge regarding health by using PEPTalk resources. Participants noted that the PEPTalk site helped in three ways: it provided new information, it provided ongoing access or the opportunity to review reliable information, and it would act as a reminder or incentive to try a new health promoting behaviour.

Fifty First Nations community members completed the web satisfaction survey in relation to the KORI website. The website scored moderately well regarding ease of use. Users found the material useful and easy to read, however, video access was problematic. Limited bandwidth in participants' communities resulted in very slow loading of the videos. While participants reported that the website material was useful, results indicated that KORI should be posting more original, locally developed material on their website.

Three major themes were identified from the quantitative and qualitative data collected from patients, clinicians, community members and staff at the three sites. These were: Valid, reliable access to health information is critical, there is a strong need for a knowledge/website facilitator for community groups and a learner-centred focus regarding website design, technology and content is essential.

A number of knowledge transfer activities have already been conducted regarding the project and future activities are planned. All three partner sites are interested in continuing to use PEPTalk with patients and community members; different sustainability models are currently being explored.

Valuable insight into the integration of online health websites in clinical and community settings was gained through this study. This form of public health education has significant implications for better utilization of scarce healthcare resources and the empowerment of Canadians in taking active roles in managing their health. We anticipate that Internet access and

the ability to customize health materials will open up learning opportunities for all Canadians but in particular for those who face traditional barriers related to literacy, education and geography.

## **INTRODUCTION**

The interconnection between health and education is well understood by clinicians in acute care and community settings. Education is a critical component of disease management and health promotion programs (Gustafson et al., 1999). A large body of evidence consistently indicates that patients who gain knowledge and skills improve their ability to manage self-care, enhance decision-making and improve their quality of life (Canadian Council on Learning, 2006). Health literacy, the ability to interpret and apply health-specific information to one's personal situation, is the basic cornerstone of health education and is critical for making health choices (Rankin & Stallings, 1996; Neilson, Panzer & Kindig, 2004).

The body of research linking education and health self- management is well established; best practice guidelines demand that health education is a key component of chronic disease management programs. These guidelines are timely as Canadians are becoming increasingly interested in learning to manage their health. The reality of achieving that goal however, is not simple at a time when clinicians have less time and resources to assist with this process. To overcome that gap, Canadians are increasingly turning to the Internet as a major tool for health education. They are accessing the Internet for standardized health information in ever-growing numbers (Woodward, 2006; Hirji, 2004).

While increased access to health information can be helpful, the quality of information retrieved varies considerably. All too often an Internet search yields unreliable, commercial information. A recent search conducted for resources to help "troubled teens" resulted in numerous hits on Google, however 85% of the resources identified were commercial (Fox, 2005). The majority of these sites offered expensive solutions that would not be recommended by health professionals. While many patients know they need to be wary of such sites, there are many who do not. Nor do most patients have the scientific background or health literacy skills needed to interpret and evaluate the information they retrieve. Many health sites presuppose a

certain level of basic, functional literacy as well; beyond the reach of users without high school reading skills.

Another disadvantage of Internet health information is the “one size fits all” phenomenon; all patients receive the same material regardless of illness trajectory, cultural background and treatment plan. Many patients are disappointed by the dearth of quality information that relates specifically to their treatment. Others are overwhelmed at the volume of information they retrieve and rapidly lose interest when reading information that does not relate to them (Hoffman, Russell & McKenna, 2004). In response to these issues, the trend towards patient-interactive systems is growing. These are systems where the patient, clinician or computer (server/Web site) individualizes patient education materials and activities for a particular patient. Another term for this approach is tailored information.

### **PEPTalk: Online, tailored patient education**

In response to the need for accessible, quality health information that is tailored to meet individual patient needs, the online patient education plan project (PEPTalk) was begun early in 2006. PEPTalk is a website that houses multimedia health information for patients and has the potential to re-define the health education process (Figure 1, 2). Just as a clinician prescribes a drug for an illness, health professionals use a database to select health information for patients to promote health and recovery from illness. Patients visit their clinician as usual, for a scheduled appointment, and as part of their visit, participate in an assessment of their learning needs. The nurse or physician ‘prescribes’ those materials that meet the patient’s need at that time. Clinicians access the PEPTalk site from a computer in their office, create a patient account, select the appropriate materials and an email message is sent to the patient advising that an education plan is waiting for them at the PEPTalk website.



Figure 1. PEPTalk: Patient home page

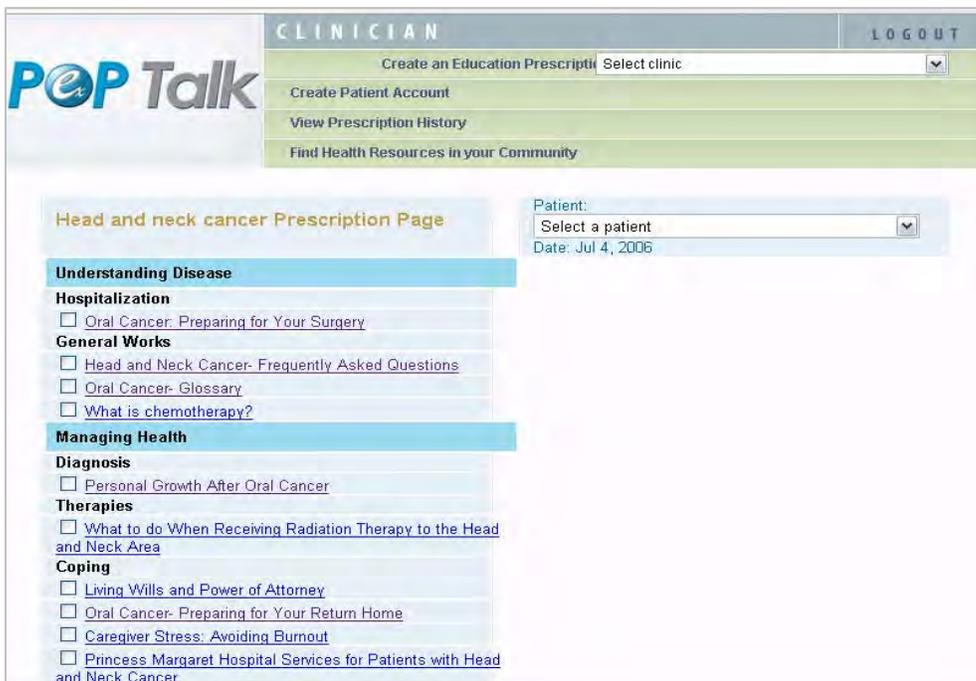


Figure 2. Clinician home page

Patients log onto the Internet from home or a community site and access their prescription. Typically the clinician will prescribe some text materials and some video-based information. Patients are not restricted to those materials prescribed for them. They are also welcome to browse the entire library of validated, online health materials on PEPTalk. If clinicians do not have computer access, they select topics on a paper version of the education plan and give this page to the patient. At home, the patient logs onto PEPTalk, enters the plan details and retrieves the recommended materials. If the patient or community member does not have Internet access, he/she is directed to a community site such as the hospital library or to a community agency where the education plan can be viewed online and then printed.

All materials on PEPTalk were developed for a Grade 6 reading level and have been written using plain language, avoiding any complex medical terminology. Since we anticipated that many people who access PEPTalk will be older or have physical changes associated with chronic illness, and come from a range of cultural backgrounds, users can customize PEPTalk for vision, hearing and limited language preferences.

Usability testing with the PEPTalk system was conducted with hospital patients. Testing measured ease of site use, usefulness of information and satisfaction and results were encouraging. Patients reported an 86 % satisfaction level (Atack, Luke & Chien, 2008). However, the introduction of PEPTalk in clinical and community settings represents a radical shift in patient education. The feasibility of offering PEPTalk and integrating it with Family Health Teams or to community participants of different socio-economic and cultural backgrounds has not yet been explored.

To determine the feasibility of offering tailored health information online through clinic and community settings, researchers from Centennial College and George Brown College, partnered with the Keewaytinook Okimakanak Research Institute (KORI) in Northern Ontario, and St. Christopher House in Toronto. They examined two patient education websites hosted by community organizations that housed valid and reliable health information. One site was the KORl website which housed health information on breast cancer from the Ontario Breast Cancer Foundation. The second was PEPTalk, developed by the research team. The purpose of the study

was to examine patient and community group members' experiences with tools offered on the KORl and PEPTalk websites to manage health and chronic illness. We examined participants' use of these online resources, their satisfaction, and the impact on health behaviour and health literacy. We also examined the experiences and needs of community staff and primary care doctors and nurses as they used these emerging technologies to support health. The study was conducted from 2007-2009.

## **Literature review**

Patient education is changing, largely because of greater consumer access to the Internet. Increasingly, the trend is towards delivering tailored, web-based health education: information targeted to an individual rather than a group. Tailored health information systems deliver information that is adapted for individual characteristics, based on an assessment of learning needs, stage of illness, treatment plan and readiness and motivation for health change (Kreuter et al., 1999). These systems have several potential advantages. A study conducted with breast cancer patients found that tailored print letters from physicians were more effective than non-tailored letters. Results showed that those who received tailored letters had better memory of their content and that they read them more thoroughly (Skinner, Stretcher & Hospers, 1994). Patients participating in a dietary study who received tailored information were twice as likely to remember they had received the information and consequently more likely to have read it. These patients showed a significant reduction in fat intake compared to those in the control group (Campbell et al., 1994). In a randomized trial to determine the impact of tailored, computer-generated information on dietary habits, researchers concluded that patients who received tailored information made significant dietary improvements. Participants also reported that the health information they received was more relevant, interesting and motivating than those in the control group who received general information (Brug et al., 1996). Another advantage of tailored Internet information is that it gives patients and families access to "vetted" information. Health information is delivered online through a protected website where materials are developed and validated by qualified health professionals. This provides a quality control process that inspires patient confidence. Findings from several recent studies consistently indicate that when quality, interactive Internet-based interventions are provided, participants gain

knowledge and improve health behaviours (Murray, et al., 2004; Wantland et al., 2004). In one study, the Internet was used to deliver counselling sessions to obese patients. Those who received counselling lost significantly more weight at the end of the year long trial than those who simply received information via the Internet (Tate, Jackvony & Wing, 2003). In a randomized control trial by Krishna et al., (2003) researchers tested the impact of an Internet-enabled, individualized action plan and multimedia materials with children with asthma. Their results indicated that children who received the intervention made significant knowledge gains, had fewer urgent family doctor appointments and Emergency room visits and required less 'urgent' medication.

A further advantage of Internet-based health information is that materials can be reviewed by the user at any time convenient to them. There are numerous studies that acknowledge that much of what is taught in even the best health teaching programs provided in acute care settings is not recalled when a patient goes home (D'haese et al, 2000; Lamarche, Taddeo & Pepler, 1998). Anxiety, distraction, fatigue, pain are just a few of the symptoms that interfere with the ability to assimilate and recall information. Health information on the Internet has the potential to overcome those barriers. Patients can review materials when they are ready to learn. They can view video of complex self-care activities such as wound care, exercises and preparing Insulin injections as often as needed. Further, family members who assist with care and were not present for initial in-hospital sessions can view these materials from home as well. This is an important advantage as patients are discharged home 'sicker and quicker' placing more of the burden of care on family members. However, while the Internet holds promise, critics of patient empowerment models have said that encouraging 'self-care' simply offloads responsibility onto patients and families who might not be able to take on this responsibility (Salmon & Hall, 2004).

Our overarching guiding principle is that, in an information rich society, we need to ensure that we provide effective patient and community health education programs, and that we measure both the positive and negative effects of the provision of online information. While there is enormous benefit in systems that generate automatic tailored information, our research shows that it is not enough to simply provide information. Clinician intervention is key to

encouraging patient compliance and uptake of chronic disease management strategies. Online tools will become an important component of public health education and will have significant implications for better utilization of scarce healthcare resources and empowering people to take active roles in managing their health (Neilson-Bohlman, Panzer & Kindig, 2004).

## **Theoretical foundation**

The theoretical foundation for our study was based on the Information, Motivation and Behavioral Skills (IMB) intervention model originally developed by Fisher and Fisher (1992) and modified by Kalichman et al., (2002). This learning model is based on the assumption that information and education are necessary precursors to developing the skills that lead to a health behaviour change. Using the Internet to access health information is perceived in itself as a health literacy behaviour change that has the potential to increase access to knowledge, enhance self-efficacy, coping skills and social support. These behaviours in turn support improved health behaviour, service utilization, and quality of life. Hill, Weinert and Cudney (2006) conducted an experiment to examine the effect of an online intervention aimed at building social support networks for women living in rural and remote areas and developing their computer literacy skills. Results indicated that women who received the online intervention reported greater self-esteem, social support and empowerment. The authors suggest that having access to the Internet for health information supports decision making and closes the power gap between provider and patient. Gustafson et al. (2001) tested online education and support for women with breast cancer. Participants gained confidence and competence in managing their health and carrying out self care measures. They were also more likely to ask their physicians questions during a clinical visit. The results suggest that online learning and discussion supports chronic illness management and can have a positive impact on the patient-physician relationship.

## **DESIGN**

A descriptive study using a mixed methods approach with surveys and interviews was conducted. Our five research questions were: What is the impact of PEPTalk and community website materials from KNET on:

- 1) patient, community member and clinician website usage?
- 2) patient, community member and clinician satisfaction?
- 3) patient self-efficacy regarding disease management and health behaviour change?
- 4) patient and community member health literacy gains?
- 5) site maintainability by clinicians or sustainability for organizations?

## Sample

The sample included two groups: *patients receiving care through a large urban Family Health Team practice and clinic* and *community members from the Keewatinook Okimakanak communities and St. Christopher House (SCH)*. The patient group consisted of those attending a family health team practice in Toronto and a hospital cancer clinic. The disease management literature indicates that patients in these groups cope better, and manage their health better with increased access to health information (The Change Foundation, 2002). This group accessed materials housed on PEPTalk.

Community members from the Keewatinook Okimakanak communities are those who occasionally or regularly use the KNet website and online communication tools offered by KNet. They accessed health promotion information linked from the KNet and PEPTalk websites. Community staff from SCH accessed PEPTalk materials. The second group of participants was *clinicians* from the Family Health Team (FHT) and clinic and *community organization staff* from KORI and SCH who referred patients to the website or facilitated access for community members.

Study participants had to be older than 18 years of age and a patient or a community member from a designated study site. Participants were excluded if they did not have access to the Internet, did not have basic computer skills or were cognitively impaired. All participants who met the eligibility criteria were invited to access PEPTalk or the KNET site by the clinician and community facilitator. The study was approved by the investigators' research ethics board and informed consent was obtained from study participants.

## **DATA COLLECTION**

A multi-method data collection approach was used that included surveys, individual and focus group interviews, website usage tracking, clinician time and patient referral tracking. The use of several data collection methods in one study is referred to as triangulation. Triangulation is particularly appropriate for a study in which there is relatively little known about the topic (Nyamathi & Schuler, 1990), and helps to provide a comprehensive picture of the phenomenon of interest (Begley, 1996). The quantitative methods, survey and patient tracking were used to answer questions regarding website usage, user satisfaction health behaviour change and health literacy change. The individual and focus group interviews were used in relation to the research questions related to user satisfaction and maintainability of the website in practice. Emphasis was placed on measuring use, usability and satisfaction as the websites under study and the clinical/community referral processes were completely new.

### **Surveys**

Patients completed the Demographic Survey and Technology Skills and Access Survey after recruitment into the study. This survey was pilot tested in the PEPTalk usability study, and includes items related to age, education, computer skills and health literacy skills such as their ability to use the Internet to find health information and their confidence in doing so. Participants were also asked to complete the Perceived Health Web Site Usability Questionnaire (PHWSUQ) after they had visited the website. The PHWSUQ was developed by Nahm, Preece, Resnick and Mills (2004). The survey measures three aspects of user experience with health websites: ease of learning the site, the utility of site resources and overall satisfaction. Satisfaction is an important concept to measure in the efficacy of online health applications because it likely influences application use and therefore may impact on clinical outcomes (Ahern, Kreslake & Phalen, 2006). Evidence for the validity and reliability of survey items have been previously reported by Nahm et al. The survey was modified during a pilot test of the PEPTalk site. The Cronbach alpha test for reliability for this usability test was .85, providing further evidence for the reliability for the survey items. Three open-ended items regarding self efficacy for chronic

disease management, health literacy and health behaviour were added to the survey (Appendix A). These included asking which components of the website would have the most impact on health, asking participants to provide an example of something new or different that they were doing, or planned to do regarding their personal health or their family's health after using PEPTalk and asking how PEPTalk helped them understand their health and live a healthy lifestyle.

## **Interviews with participants**

Ten individual interviews with three clinicians and four staff were conducted using semi-structured interview guides. The clinicians were interviewed twice to gain their perspectives when they were new to the PEPTalk referral process and again later when they had become familiar with the PEPTalk process to track changes over time. Participants were asked to describe their experience with the websites, difficulties or concerns, the impact of the website on their patients' or members' health knowledge and health behaviour. Participants were also asked to describe how they integrated the website referral process into their practice and the impact of this process on their workload and clinical/community practice (Appendix A).

Focus group interviews were conducted with family physicians and community participants. The purpose of the focus groups was to gain an in-depth understanding of family doctors' and SCH community members' and staff use of the Internet, barriers and health information needs.

## **Website usage**

PEPTalk log data, including overall statistics regarding the number of visitors who logged onto the website and the number of files accessed per individual were documented for patients in the study.

## **Maintainability**

Clinicians used a numbered education prescription plan to ‘prescribe’ topics on PEPTalk. This enabled them to record the numbers of referrals to PEPTalk and the time spent on this task.

## **DATA ANALYSIS**

As this was a mixed-methods design, both qualitative and quantitative data analyses strategies were used. All interviews were taped and transcribed. The interviews were then coded using each participant sentence as a unit of analysis and a content analyses was conducted to identify major themes within and across participant groups. Descriptive statistics were calculated for the demographic survey, the PHWSUQ, physician referral numbers and web log data. This provided a profile of study participants and a report of participants’ satisfaction with the websites.

## **RESULTS**

Results have been organized into two sections. Part 1 includes results from the needs assessments conducted with family physicians and community members to explore feasibility and implementation issues prior to introducing PEPTalk. Part 2 includes results from PEPTalk and KORI website implementation initiatives.

### **Part 1: Needs Assessment Results**

#### **Needs assessment: family physicians**

The first step in introducing technology is to gain an understanding of user's circumstances and needs. Family physicians who were attending the Ontario College of Family Physician Annual Scientific Assembly in Toronto in November 2007 were invited to attend a focus group interview to learn about PEPTalk and discuss the Internet as a health information tool. A convenience sample of eight participants joined the one hour session facilitated by the researchers. The focus group approach was chosen to create a relaxed, collegial environment that would encourage different perspectives on PEPTalk and provided a feasible venue for demonstrating the PEPTalk application. The demonstration was followed by a discussion of the Internet as a health information tool and issues arising in practice.

### ***Participant profile***

Physicians' average number of years in practice was 13.6 with a range from 6 to 26 years. Six participants (75%) described their practice setting as urban, 1 (13%) as rural and 1 (13%) as suburban. Their practices were situated in Toronto (3) as well as Kingston, North Bay, Dundas, Ottawa and Pickering. Ages ranged from 36 to 55 with the majority aged 50 or less. Three (38%) were female; five were male.

### ***Internet use in practice***

All participants stated that they used the Internet for health information as a resource for their patients. In some cases this meant referring patients to websites, in others, retrieving website information and printing it for patients during a clinical visit. The major concern raised was the need for reliable, trustworthy health information. The physicians reported that they, and their patients, are overwhelmed by the volume of health information on the Internet and that much of what they retrieve is out of date, biased or incorrect. The participants were aware of some commercial sites that provide quality information but they reported these as being "too expensive," about \$700 per year.

Several physicians reported using sites such as the Ontario Heart and Stroke website and Healthy Ontario. The information on these sites was judged as reliable and useful. Participants

also send patients to other sites, however, because they do not have time to check each piece of information on these sites, they were not confident or satisfied with this process. They find they generally have to print the health information for their older patients who do not use the Internet.

### ***Physicians' response to PEPTalk***

The participants found the concept of a site that houses information that had been 'vetted' or approved by clinicians, very appealing. *"It's a great idea, we don't have time to talk to them [patients] about everything they need."* A resource such as PEPTalk would address their concerns about sending patients to sites that they had not validated themselves. *"It would be really nice not to have to go through everything on a site"*.

Further, several physicians commented that tailored health information to meet specific patient needs is more effective than a 'broadcast' approach. They believe that approaches to health education will become increasingly tailored and will gather momentum in the years ahead. They were however, pleased to hear that patients are not restricted to materials 'prescribed' by the clinician on PEPTalk; patients are welcome to browse all health information on the site.

While enthusiastic about PEPTalk, participants were concerned that prescribing tailored patient education would add a significant amount of time to an already busy clinical visit. *"Time and practicality are important; I don't see docs taking time to do this"*. Whatever resource they adopt, they emphasized that it must be embedded in the clinical visit and it must be simple and quick to use: *"It has to take less than one minute"*.

Another issue was Internet access: some physicians did not have a computer with Internet access in their office. They were interested to learn that while a physician can select resources electronically on PEPTalk in the office, a simpler paper option is also available. The participants were also interested to hear that PEPTalk is Internet-based; they would not need to purchase or download any software to use the site.

### ***Important features in a health information site***

Participants noted that the ideal health information website would include the following features:

- An index that would inform them of the resources on the site so they could quickly determine what was available.
- A fast and efficient search engine to pull up resources quickly
- Stocked with credible, up to date health information: The issue of trusting health information was an important one. Participants want to see evidence that resources on the site have been reviewed by a reputable source so they do not have to review every item on the site. They don't have time for this nor are they experts in all areas.
- Evidence that content is updated regularly and the date of the last review is apparent
- Information is presented in plain language, without jargon, so it is accessible to all patients
- Graphics to support text information are helpful
- The site must be secure
- The site is ideally integrated into the electronic health record
- There is no sign of commercialization on the site
- The site includes a disclaimer reminding patients that physicians are not responsible for information on the site and that in addition to using the website, patients need to talk to their doctor

### *Content areas*

Participants identified the following categories of health information that they frequently give to patients and which would be helpful on PEPTalk:

- Disease progression management information
- Self monitoring tools information on basic health promotion (smoking cessation, diet, exercise, stress management etc.)
- Mental health information.

### *Issues/Questions*

Participants raised some issues about the health information site. These included:

- Who pays for access to the site?
- What would be the cost?
- How will physicians be compensated for their time in referring patients to health information sites?
- It will be important to fund the site so resources are monitored regularly and kept up to date.
- It would be better to limit resources on the site, doing a good job with fewer resources than trying to do it all.
- The idea of having their own ‘folder’ with their own favourite health information was very appealing. This would be a quick way to refer their patients to resources they found particularly useful.
- Physicians do not want emails from patients

The small sample who participated in the focus group may not be representative of the larger population of family doctors and therefore results cannot be generalized beyond this particular group. The results do however, provide an understanding of the physicians’ experiences and needs regarding using the Internet for health information. Findings from the needs assessment validated the purpose and design of PEPTalk as a health information resource. The information learned from the session provided useful direction for the implementation of PEPTalk with patients in the study.

### **Needs assessment - Community members and staff**

A second needs assessment, using focus group interviews and surveys, was conducted with community members and staff at our partner community site, St. Christopher House (SCH), a social service agency in Toronto. Two focus group sessions were held with 10 participants at SCH and the sessions each lasted one to one and a half hours. The purpose of the focus groups

was to gain an understanding of community members' and SCH staff use of the Internet, barriers and health information needs.

Four community members completed a short demographic/computer experience survey before the focus group session began. Community members ranged in age from 42 to 62 with a mean age of 55.2 years, three men attended and one woman. English was the first language for just one participant. Two members had completed high school and two had a college or university education. The health information areas participants' indicated as being of most interest included: pulmonary fibrosis, heart and stroke, arthritis, fungal problems, medications and arthritis. None of the participants had a home computer. On a scale from 1 (beginner) to 10 (expert) the average score for the item, "*skills in using the Internet to find information*" was 4.5; the range of scores was 1 to 8. The mean score for the item, "*Interest in using the computer for health information*" was 8 out of a maximum of 10. The mean score for the item, "*Confidence using the Internet to find health information*" was 6.2, the range 4 to 9 out of a possible 10. Three participants reported using SCH or another community centre to access a computer for health information, two used a computer at the local library as well.

It is interesting to note that although the average rating for Internet search skills was reported as 'medium', participants reported a fairly high degree of confidence in using the Internet and stated they were largely confident and knowledgeable about their health. Because the group self-selected to participate in the focus groups it is likely that those who were more comfortable with the Internet chose to attend the session.

### ***Focus group themes: community members***

#### **Internet search process is a challenge**

The major issue that emerged for community members was that searching the Internet for health information is difficult, and time consuming, especially for those where English is a second or third language and for older members (Table 1). They know how to search, however,

they retrieve a lot of unreliable or incorrect information. *“Most of it’s garbage. I’ve spent hours and hours going through the garbage ‘till I find something that looks reasonable. Then I’ve spent hours and hours with that reasonable thing searching authors of the site...is it a doctor, a pharmaceutical company behind it? Or is it mom and pop who just learned how to put a website together?”* Another participant commented, *“I hope I can find it [on the Internet] right away, without looking through many things. We need right away...we are old...if something is very important, we can’t wait.”*

Another finding was that participants do not trust the information they retrieve. Frequently, the source is not apparent on a website or they were not clear how to evaluate the source. They were concerned that what they retrieve is from a commercial source and therefore biased. Participants were interested in mainstream health information but also validated information on complementary therapies for those situations when they have been told traditional medicine has done all it can. *“If it’s my health and I’m trying to find an answer I want that kind of [reliable] stuff. I don’t want the miracle pill that will cure me for \$ 9.99.”* They expressed a need for expert guidance to assist with retrieving valid health materials.

### **Access is a barrier**

None of the participants had home access to a computer; they relied on community agencies such as SCH and libraries for access to Internet-based health information. The need for materials in participants’ first language was also described as important. The need for a support person at the community agency to assist with Internet health searches was raised if the search process cannot be simplified.

### **Health information design**

While retrieving accurate, reliable information takes priority, the appearance and presentation of health information is important. Participants want materials presented in simple, plain language, with a non-cluttered, but appealing screen layout. *“I think you would just be satisfied if you get the right answer, just the plain text would be enough...Easy to read.”*

## **Privacy and security**

While the idea of Internet- based health information that could be tailored for them as individuals had appeal, concerns about the security of their health information and search results was expressed.

**Table 1. Internet education needs assessment themes: Community members**

<ol style="list-style-type: none"><li><b>1. Internet information search: a challenge</b></li><li><b>2. Access is a barrier: hardware and literacy</b></li><li><b>3. Health information design</b></li><li><b>4. Privacy and security</b></li></ol>
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## **Focus group themes: Community staff**

Six community staff from SCH participated in the focus group interview. Their roles included; Home support team leader, Coordinator, Day program for seniors, Assistant coordinator, seniors program, a community development student on placement, a seniors' community development leader, and the adult literacy programs program leader

## **Technology access and literacy are barriers**

The consensus among participants was that Internet use in their programs was typically low. Participants identified several factors influencing Internet use for SCH members. These included: No computer access at home, low English language skills and low literacy skills, low computer literacy skills, and the largely senior population attending programs led by focus group participants.

SCH community members are largely new immigrants to Canada; for many, their budgets do not extend to owning a computer and having Internet service. Portuguese and Vietnamese are the first language for many members so this limits their ability to search and retrieve health information on the Internet. Further, the staff participating in the focus groups largely worked with seniors, the majority of whom do not have Internet skills or access.

### **Scope of practice**

Staff noted that using the Internet for health information is beyond SCH staff scope of practice. While some staff reported that they use the Internet at work to retrieve health information, it is usually for referral purposes rather than to provide specific health information for an individual community member. Providing or interpreting individual health information is outside the scope of practice for community staff. One participant commented, *“There are privacy issues, we are not supposed to discuss personal medical information with our clients. Nor to give them any advice.”*

### **Internet use**

Community staff elaborated on the ways they use the Internet in the workplace. This included identifying community resources and services for community members, locating health information as part of program activities provided by SCH in pamphlets and workshops and identifying local health professionals to facilitate community workshops. The greatest use of the Internet for health information was to identify material that can be used at health promotion workshops related to diet, exercise and healthy living. This information is shared during presentations and through pamphlets.

### ***Internet-based information: The essentials***

The staff noted that there are a number of aspects or features regarding health websites that are important to them when they use the Internet for community work. These included:

- Reliable health information from a credible source
- Health information presented in simple, clear terminology (no jargon)
- Information is available in multiple languages (Portuguese and Vietnamese in particular).
- Graphics are meaningful and augment understanding of the text
- Screens are clear, appealing, uncluttered and not “busy”
- Internet information is formatted to be easy to print

Of major importance was the notion of being able to trust the information retrieved from the Internet. Participants expressed concerns about getting information from commercial sites, such as those sponsored by drug companies, which they suspected might be biased. They reported that they felt comfortable with their own Internet evaluation skills. They try to develop these skills in their members, however, this would be an important potential area for development. The Toronto Public Library provides sessions on the topic but registration is required, the sessions are general and do not focus on health.

The focus group interviews provided valuable information on the Internet health-based information needs of community members and staff. There was considerable overlap of issues identified by staff and community members. Results of this stage of the study provided direction for the project team for implementation.

## **Part 2: Technology Implementation**

This section of the report discusses results from the technology initiatives introduced in the project with the KNET website and PEPTalk (Table 2).

**Table 2. Profile of study sample**

<b>Study Stage</b>	<b>n</b>	<b>Participant groups and website</b>
<b>Part 1: Needs assessment</b>	18	Physicians, community members and staff
<b>Total</b>	<b>18</b>	

<b>Part 2: Implementation</b>	50	KNET community members: KNet site
	29	Patients: PEPTalk site
	15	KORI community members: PEPTalk site
	8	Community staff: PEPTalk site
	7	Clinicians/community facilitators: PEPTalk
<b>Total</b>	<b>109</b>	
<b>Study total</b>	<b>127</b>	

*Keewaytinook Okimakanak community members*

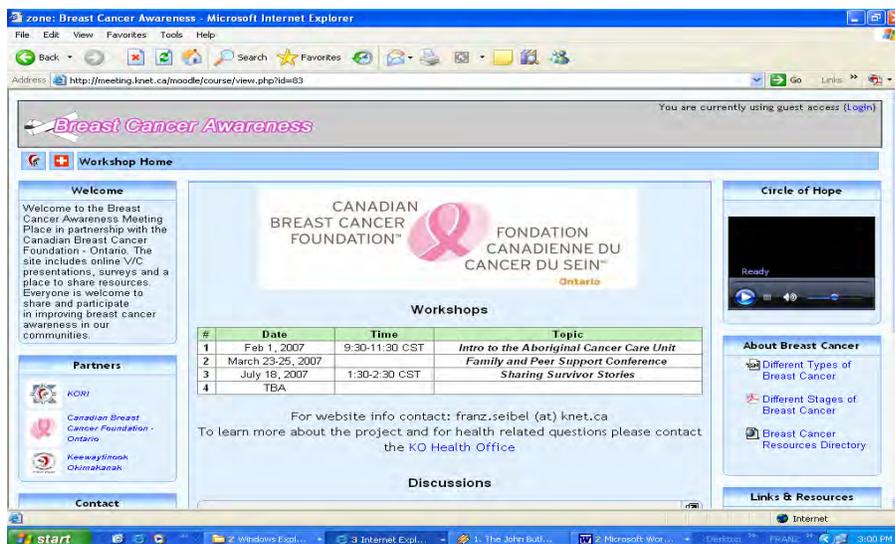
Two tools were used in this study to promote access to health information: the KORl Breast Cancer Awareness website and PEPTalk. The KORl Breast Cancer Awareness website was developed by KORl for the Nishnawbe Aski Nation peoples, to raise awareness of breast cancer by sharing information through online resources, links and videoconference workshops. Sessions were held in different communities by community researchers to introduce the website (Figure 3).



**Figure 3. Nashniwabe-Aski Nations**

Using culturally appropriate sharing circles, community members were directed to the KO website and encouraged to examine materials from the Breast Cancer Foundation of Canada, Ontario chapter. They also reviewed a slideshow called *Breast Cancer Stages* and a video developed in partnership with the Northwestern Ontario Regional Cancer Centre and Cancer Care Ontario called *Circle of Hope* (Figure 4).

Participants were asked to give feedback regarding the appearance of the website home page and site pages, the way information was presented and the utility of information. They were also asked to comment on how easy or difficult it was to read and understand the information presented on the site and to operate the video. Lastly, they were asked to make recommendations to improve the website. KO researchers made notes during the discussion, collected and analyzed survey data. After spending time on the site, participants then completed the PHWSUQ survey which was translated, as required, by local coordinators who guided participants through the survey.



**Figure 4: KORI website: Breast Cancer Foundation of Canada, Ontario chapter materials**

### ***Results KORI breast cancer awareness website***

Fifty participants from several First Nations from KO affiliated communities and the Sioux Lookout, Red Lake and Thunder Bay Health Zones communities participated in the study (Table 3). The results provide insight into the Breast Cancer Awareness website's layout, content and effectiveness as well as the health information habits and needs of Nishnawbe Aski Nation First Nations peoples.

**Table 3. Survey Participants by Band Membership & Tribal Council**

<b>NAN Independent Bands</b>	<b>Independent First Nation Alliance</b>	<b>Matawa</b>	<b>Keewaytinook Okimakanak</b>	<b>Windigo First Nations Council</b>	<b>Other</b>
Mishkeegogama ng First Nation	Kitchenuhmaykoosib Innuwog First Nation	Eabametoong First Nation	Deer Lake First Nation	Bearskin Lake First Nation	Manitoulin Island
		Long Lake #58 First Nation	Fort Severn First Nation	North Caribou First Nation	Thunder Bay
		Marten Falls First Nation	Keewaywin First Nation		Lac La Croix First Nation
		Neskantaga First Nation	Poplar Hill First Nation		Balmertown
			North Spirit Lake First Nation		

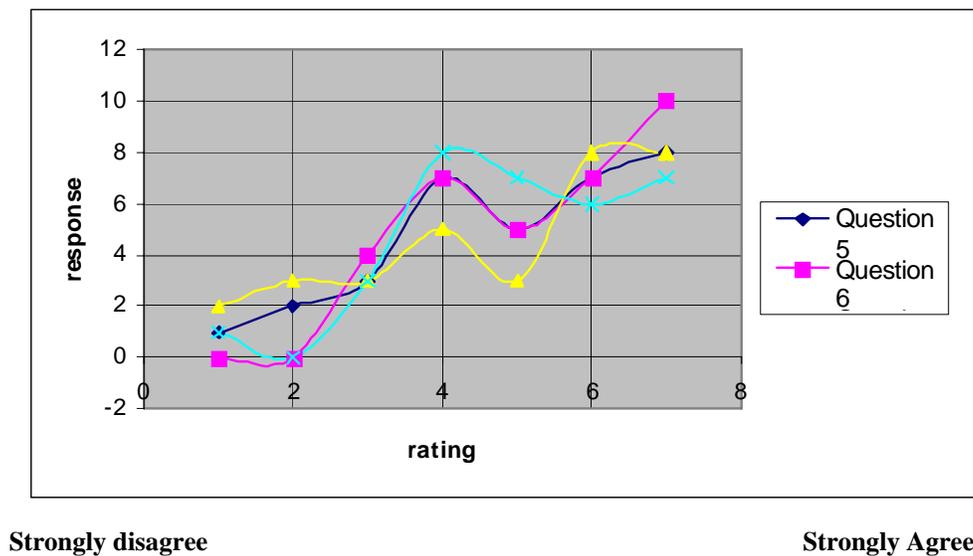
Twenty-nine (59%) participants indicated that they regularly use the Internet to find health information. They identified a number of barriers to finding health information on the Internet, including access to a computer and/or the Internet, and lack of computer/Internet skills. Fifty-eight percent indicated they had greater than average Internet skills; 12% identified themselves as expert Internet users. Fifty-four percent indicated that they had a greater than average confidence level regarding using the Internet. Forty-one percent indicated that they had accessed online health information less than five times in the last month, 37% had accessed 5 to 10 times in the last month, and 22% had accessed information over 10 times.

***Results: Perceived Health Web Site Usability Questionnaire***

Participants also completed the Perceived Health Web Site Usability Questionnaire (PHWSUQ).

## Ease of use of online material

Participants were asked to rate the ease of finding information on the KORI website, ease of reading information retrieved, ease of viewing video clips and the ease of learning to use the website (Figure 5). The website scored moderately well regarding ease of use. Ability to access video received the lowest score and the ease of reading the information provided received the highest score.



**Figure 5. Ease of use in finding (Q 5), reading (Q 6) viewing video (Q 7) and ease of learning the site (Q 8).**

Participants indicated that the most helpful parts of the website were the discussion area and the online videos. They indicated that there were technical and design challenges with the site. One major technical problem that was identified was limited bandwidth/Internet access in their communities, resulting in very slow loading of the videos. Other issues that were identified were incompatible browsers and needing to install video plug-ins. They indicated that the Breast Cancer Awareness website takes a long time to load especially in remote and isolated First Nations communities where broadband access is limited and shared among many local users. Participants made recommendations regarding content, layout and design, and technical requirements. They suggested that the site needs to be more visually appealing with more photos,

videos and graphics. They requested that more resources be located on the site rather than to external links. They also suggested that the site be made easier to find, with a shorter URL or a link from the main [www.meeting.knet.ca](http://www.meeting.knet.ca) page.

### **PEPTalk implementation: Keewaytinook Okimakanak community members**

Community members and health care workers in the region were given access to the PEPTalk website by the KO partner community researcher. Fifteen visited PEPTalk and completed the PHWSUQ survey; the maximum score is 5 for each item.

KORI participants ranged in age from 21 to 69 with most (n = 8; 53 %) in the 40 to 59 age range. Two were male (20%) and 13 (80%) were female. Eight-seven percent (n = 13) reported English as their first language. Grade school was indicated as the highest level of education reached for most participants (62%, n = 8), four (31%) indicated high school and one (7.7%), college or university. Eighty percent (n = 12) had Internet access at home, the remainder did not. Twenty-six percent (n = 4) participants identified themselves as ‘beginner’ Internet users, forty percent (n = 6) as ‘intermediate’ and thirty-three percent (n = 5) as ‘expert’. The mean for time spent on PEPTalk was “1 -2 hours’ (SD= .41) and the range was less than one hour to two hours. The mean score for the total PHWSUQ was 38.4 out of a possible 50 (SD=4.5) and scores ranged from 32 to 45. Mean scores of survey items appear in Table 4.

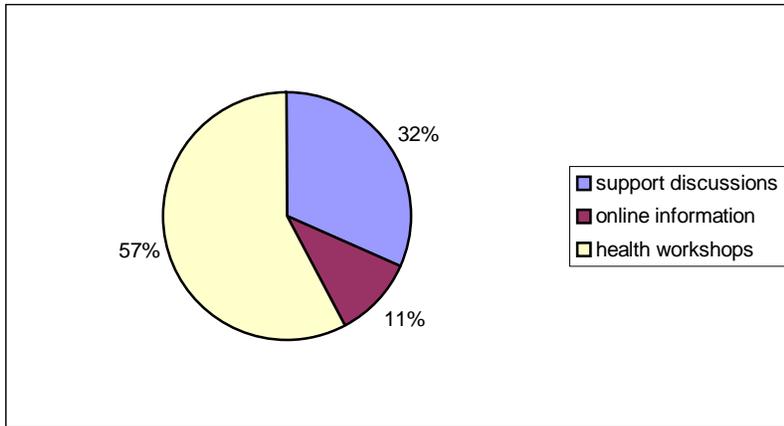
**Table 4. PHWSUQ results: Keewaytinook Okimakanak community**

<b>Item</b>	<b>Mean ± std</b> <b>(1 =strongly disagree 5 = strongly agree)</b>
It is easy to find information on the PEPTalk website	3.9 ± .79
It is easy to read the information provided	3.8 ± 1.0
The overall appearance of the site makes it easy to use	3.1 ± 1.3
The information I was directed to was relevant to my health at this time	3.8 ± .91

The information presented on PEPTalk is useful	4.4 ± .63
I have confidence in the material presented on the PEPTalk website	5 ± .00
Overall I found it easy to learn to use this website	3.4 ± .83
This website has improved my knowledge about health	4.2 ± .79
This information on the website will help me maintain better health habits	2.7 ± .59
I would recommend this website to others who are seeking reliable health information	3.7 ± .88

All participants strongly agreed with the item, *“I have confidence in the material presented on the PEPTalk website,”* and most agreed the content was useful and improved their knowledge about health. However, some items had low scores including, *“The overall appearance of the site makes it easy to use,* and, *“Overall I found it easy to learn to use this website.”* The results indicate that further design work to simplify the site, to make it easier to navigate.

The item, *“This information on the website will help me maintain better health habits”* also received a low score, implying that it might be too early to judge the utility of PEPTalk after a brief, initial experience and that web-based materials are only part of an overall community-based strategy that is needed to help people change their health behaviour. Just 11% of participants identified online information as a key component of health initiatives (Figure 6).



**Figure 6. Key components of health initiatives**

The PHWSUQ included four open-ended items where participants were asked to comment on what they were doing, or going to do, with the health information they acquired from PEPTalk, how the information on the site would help with health management, what was useful/not useful and what changes and comments they would like to make regarding the site. Participants were positive; 11 out of 15 gave an example of how they would use PEPTalk information. They commented that the information they had learned would help with disease management situations such as diabetes and cancer, as well as family health concerns such as pregnancy, newborn care, parenting and eldercare. Two participants noted that they planned to use site materials in a professional capacity as health councilors. Some participants said that they had already, or planned to, print information for family members. Content areas that were particularly useful were diabetes, mental health and health promotion content such as nutrition and family care. One participant noted, *“I liked the healthy eating information and examples. I’m going to look up some new recipes.”* Another noted, *“[I can use it to] help the elders that I take care of.”*

Several recommendations were made to improve the site from this community’s perspective. These included: developing more First Nations- focused material, developing more content on exercise and more mental health material related to suicide, alcohol and drug abuse, aimed at youth. Design recommendations included making the site more visual; one respondent commented, *“It looks very academic,”* and avoid using pdf files. Some participants questioned the rationale for the login process. Technical problems were reported by 11 participants. They

noted that they have low bandwidth in their communities had made downloading files and viewing video difficult and frustrating. Some participants reported login difficulties as well.

### **PEPTalk implementation: Family physician patients/clinic patients**

Patients who visited a family doctor/clinic in the Greater Toronto Region were assessed for study eligibility. Patients' learning needs were assessed during the clinical visit and the physician "prescribed" recommended resources on PEPTalk. While the process of prescribing materials can be done electronically, the clinicians in this project found it more expedient to select appropriate topics on a paper education "prescription pad". The paper version was developed specifically because many physicians do not have a computer with Internet access in each exam room or clinic office. Each page of the prescription pad contains the items from the website which can be selected or checked. The clinician gave that page and PEPTalk login instructions to the patient during the clinical visit. At home, the patient logged onto PEPTalk, created an account, and retrieved the recommended materials. Physicians tracked the number of patients were referred to PEPTalk and reported 87 referrals. Of those patients who were referred, 29 (33%) logged onto the PEPTalk site. Those logging onto PEPTalk accessed on average 3 items (SD 4.9), however the number of items accessed ranged from 0 to 20. The median was 2 and the mode was 0 (eight did not access any files). Two patients each accessed 20 files.

Eleven patients (38%) of those who logged on completed the PEPTalk satisfaction survey. Those patients who completed the survey ranged in age from 21 to 79. Fifty-five percent (n = 6) were male, 45% (n = 5) were female. Seventy-three percent (n = 8) reported English as their first language, 27% (n = 3) indicated otherwise. Forty-five percent had completed high school and 55% college or university. Eighty-two percent had Internet access at home, 18 % did not. Two (18%) participants identified themselves as 'beginner' Internet users, four (36%) as 'intermediate' and 5 (46%) as 'expert'. The mean time spent on PEPTalk was "one to two hours" (SD 1.4) and the range was less than one hour to more than five hours. Patients completed the PHWSUQ (website satisfaction) survey. The mean score for the total survey was

40.4 (SD4/7) out of a possible 50. Scores ranged from 33 to 48. Mean scores for each item are presented in Table 5.

**Table 5. PHWSUQ results: Patients**

<b>Item</b>	<b>Mean ± std</b> (1 =strongly disagree; 5 = strongly agree)
It is easy to find information on the PEPTalk website	3.8 ± 1.01
It is easy to read the information provided	4.1 ± 1.1
The overall appearance of the site makes it easy to use	4.2 ± 0.42
The information I was directed to was relevant to my health at this time	4.3 ± 1.05
The information presented on PEPTalk is useful	4.2± .632
I have confidence in the material presented on the PEPTalk website	4.3 ± .672
Overall I found it easy to learn to use this website	4 ± .000
This website has improved my knowledge about health	3.8 ± 1.03
This information on the website will help me maintain better health habits	3.7 ± .674
I would recommend this website to others who are seeking reliable health information	4.1 ± .737

Seven items had a mean of 4 or greater, suggesting that patients were satisfied with most aspects of PEPTalk. The items with a mean of less than four included, “*It is easy to find information on the PEPTalk website*,” “*This website has improved my knowledge about health*” and, “*The information on the website will help me maintain better health habits.*” The results indicate that further design work to simplify site navigation is needed and that it might be too early to judge the utility of PEPTalk after a relatively short, initial experience and that web-based materials are only part of an overall strategy that is needed to help people change their health behaviour.

The PHWSUQ included four open ended items where participants were asked to comment on what they were doing that was new/different after using PEPTalk, how information on the site would help with health management, what was useful/not useful and what changes and comments they would like to make regarding the site. Nine of the eleven patients gave an example of something they were doing that was new or different such as dietary or exercise activities. They noted that the site helped in three ways: one way was that it provided new information to assist with decision making regarding a health behaviour., One patient noted, *“-I can check about diet, or symptoms and like in my personal case, how much snacking could make my blood sugar rise without me knowing about it,”* Another noted, *“I’m following a back exercise regimen on regular basis.”* A third noted, *“It’s a good reference tool to make sure I am feeding her [her baby] the right food and the right amounts.”*

Patients also noted that the site provided ongoing access or the opportunity to review reliable information, and the site would act as a reminder or incentive to try a new health promoting behaviour. One patient commented, *“Instead of waiting for a doctor’s appointment, I can look up answers to my questions and sometimes just being able to go back and see what was it I was told but forgot already.”* Another commented, *“While this will not be my primary source of information, I like the fact that it is linked to my doctor and she can see what I am researching so we can discuss it at appointments.”* A third noted, *“I thought it was a good resource from a trusted health professional to confirm all the information that is available on the web or that is passed to you from others.”* Some patients reported technical problems through the help desk such as difficulty accessing the site, password malfunction and videos slow to download when using a dialup connection. They recommended that content be kept short for each topic module and that a content index should be developed to facilitate the search process.

## **PEPTalk implementation at SCH**

Seven personal support workers, one program coordinator and one social work student, with ages ranging from 32 to 59 were given access to PEPTalk at SCH. All said that they used the Internet regularly for health information. The support workers provide care in the community

to SCH members and often receive questions from clients and requests for health information. Beyond the basics, health information is not part of their training.

A focus group session was held where a demonstration of PEPTalk was given and participants could browse both text and video materials on the site. After the session, participants completed the PHWSUQ and participated in a one hour focus group session to discuss their reactions to the site. Mean scores for each item are presented in Table 6.

**Table 6. PHWSUQ results: SCH**

<b>Survey item</b>	<b>Mean ± std (1= strongly disagree; 5 = strongly agree)</b>
It is easy to find information on the PEPTalk website	4.7± .46
It is easy to read the information provided	4.8± .35
The overall appearance of the site makes it easy to use	4.7 ±.46
The information I was directed to was relevant to my health at this time	5 ±.00
The information presented on PEPTalk is useful	4.6 ±.51
I have confidence in the material presented on the PEPTalk website	4.7 ±.46
Overall I found it easy to learn to use this website	4.8 ±.46
This website has improved my knowledge about health	5.0 ±.00
This information on the website will help me maintain better health habits	4.8 ±.44
I would recommend this website to others who are seeking reliable health information	4.8 ±.35

Results for each item were very positive; the total mean score for the survey was 48 (SD 1.2). Reasons for the results are explained through the focus group interview that is reported later in this document.

In summary, two health information websites were introduced and evaluated using surveys that included open-ended items with three groups, patients attending a family doctor and cancer clinic, community members and staff from Keewaytinook Okimakanak community in Northern Ontario and St. Christopher House in Toronto. Caution is needed when comparing results across sites as the web resources were used in different ways by patients and community members. However, results from the PHWSUQ survey were very similar for many survey items. Participants generally found the information provided was useful, relevant and had improved their knowledge about health. They indicated that they had a high degree of confidence in the materials and would recommend the site to others.

One area where results differed was the very low score for the item, “*This information on the website will help me maintain better health habits*” by KO participants. A comparison with results from feedback on the KNET Breast Cancer site suggests that participants feel that health information websites should be a part of a broader umbrella of educational resources. Further, community members favour a more interactive approach to health education. The research team had considered engaging participants in video conference workshops to discuss the resources after they had been accessed on PEPTalk. It is possible that the web-based resources, supported by follow-up discussions with support people and clients could improve the effectiveness of the website in affecting health behaviour change. KO users also reported more technical problems with the site than Toronto-based users; specifically slow file downloading related to low bandwidth access. This finding was also reported by those who participated in the survey evaluating the KNET breast cancer website.

## **Interviews**

Clinicians, staff and community members participating on the project were interviewed to gain an in-depth understanding of their use of online health information, experience with PEPTalk and recommendations. Ten interviews were conducted overall. Six interviews were conducted with two physicians at different stages of PEPTalk implementation, and one interview each was conducted with a clinic nurse, the Director of Knowledge Support Services at the

Centre for Effective Practice, as well as a community researcher at KORI, and the program coordinator at SCH. All interviews were taped, transcribed and a content analysis was conducted to identify major themes. The themes were shared with community participants to see if their experiences had been accurately captured.

## **Interviews with physicians**

### ***Experience with PEPTalk***

Two physicians were interviewed for the study at early stages of PEPTalk implementation and again after three months. The two doctors were experienced family practitioners who regularly access websites and print materials or give patients URLs to review at home. These physicians provided content or content topic suggestions in the planning stage of the project and those materials were housed on PEPTalk. One physician said she told patients that she had read all the material on PEPTalk, was confident with it and that she was looking for ways to communicate with patients outside the office, to improve their health. Her normal practice was to go to a website, download, print info and give that to a patient. Her thoughts regarding PEPTalk were that, *“This might even save me some time.”*

Physicians described the patient referral process they had followed. They assessed the patient, determined their learning needs with the patient and ‘prescribed’ relevant materials on PEPTalk by checking off items on a paper education plan. Patients took the plan and login instructions home, where they created an account and accessed PEPTalk. Usually the process went smoothly, however, physicians identified activities that had interfered with their ability to refer patients to PEPTalk, such as supervising residents and heavy clinic patient volumes. They estimated that referring to PEPTalk adds about three to four minutes to a clinical visit. *“If I’m running behind, it’s very difficult for me to incorporate it.”* They acknowledged that their time however, might have otherwise been spent visiting the Internet and printing materials previously.

They identified several advantages of PEPTalk, the primary being able to offer reliable, evidence-based information that they were comfortable with to their patients. They commented

that their patients felt more secure knowing that the materials had been vetted by their own doctor. They felt PEPTalk could positively affect a patient's health however, patient education materials on PEPTalk had to be integrated into the overall health care plan. One physician noted, *"Information on its own, without an action plan or follow-up does not change patient behaviour."* Another benefit of PEPTalk that was identified was that the physicians supervise many new residents every year. Putting their top ten most needed topics on PEPTalk meant that their residents would have easy access to reliable, quality patient information, all in one place.

### ***Barriers and challenges***

While being positive overall about PEPTalk, the clinicians identified a number of problems or barriers to success or reasons why uptake of PEPTalk had not been as great as anticipated.

They identified several patient-related barriers: a large number of their patients did not qualify for the study: they did not have computer/Internet access or they did not speak or read English. Further, PEPTalk requires the patient to be an active participant in his/her care. Instead of simply accepting a brochure, the patient has to take the education 'prescription' home, logon to PEPTalk, create an account and then access the materials prescribed. Physicians speculated that many patients were not motivated to follow up with PEPTalk once they got home. They also speculated that the multi-step process might be another barrier. One physician commented, *"I think it's a time thing, they don't have the time or they are not that interested. They are interested when they talk to me but when they get home, they put it [education plan] in their pocket and forget about it, they don't go back to it. So, it's more active on their part."* They also thought that some patients were simply not ready for PEPTalk; they were overwhelmed by health or other personal issues and not ready to learn a new process that involved technology.

On the technical side, in some cases, the PEPTalk database, while large, did not include some topics physicians wished to prescribe. The physicians had also received feedback from some patients at subsequent visits that they had encountered technical problems with the site. The site was not 'up' or loaded slowly at times.

A barrier for the physicians was the design of the ‘education prescription pad’ with its long list of topics. Suggestions were made to group related topics into folders to improve the search function. One clinician said that instead of using the prescription list, she would like to be able to write down one or two words on a piece of paper and the patient would search for those terms on PEPTalk at home. She acknowledged however, that while this approach would perhaps make prescribing and retrieving health information quicker, it would reduce some of the tailoring features of PEPTalk.

### ***Future directions***

Physicians were asked to share their thoughts on the further development of PEPTalk. High on the list of features they would like would be an interface with PEPTalk and the electronic medical record. This would provide documentation regarding patient education which would have recordkeeping as well as legal benefits. The suggestion was made to ‘push’ out information to patients by sending prompts to patients advising them of what was new on the site and to remind them to visit the site. Other suggestions included ‘leveling’ the content on PEPTalk for the patient’s literacy level. Currently, all materials on PEPTalk are developed for the grade six reader. Clinicians indicated they had patients who wanted higher level, in-depth coverage of topics. Adding more content on favourite resources such as childcare, pregnancy, and exercise would also make the site more useful for family physicians.

## **Interview with clinic nurse**

### ***Experience with PEPTalk***

Another clinician on the project was a head and neck cancer clinic nurse who referred patients to the project. He described how PEPTalk had been integrated into the clinical process. Originally, they used PEPTalk with patients when they were first diagnosed, however, they soon realized that patients were overwhelmed by their cancer diagnosis and not ready to learn. They then introduced PEPTalk about two weeks later, after the patient had been diagnosed and

consented to surgery. The nurse saw them when they came to the preadmission department. During that visit, the clinic nurse described the purpose of PEPTalk, what the site offered, ‘prescribed’ the appropriate education module and emailed start-up information to the patient at home. From there, the patient, or a family member, accessed the site.

The nurse’s experience with PEPTalk’s design and content had been positive. Head and neck cancer patients and their families are required to carry out some very complex feeding and wound care activities after surgery, on discharge home. Several videos had been developed for the website, demonstrating post-operative self care activities. The ability to review demonstrations of self care as often as needed was reported as the most helpful feature on PEPTalk. This feature helped patients but also their family members who manage the patient’s care on return from hospital. The nurse recommended that patients receive access to all content on the site, not just head and neck care materials, as patients have other health issues such as diabetes and high blood pressure. The nurse commented on the benefits of PEPTalk, he remarked that improving access to health information is ‘empowering’ for patients and encourages them to be active in their care.

### ***Barriers and challenges***

The nurse encountered major technical problems with the site; access was not reliable and the login process failed at times. The special characteristics of the head and neck patient population also influenced PEPTalk uptake. Many patients attending the clinic are older, living in modest circumstances, and they do not have access to a computer or the Internet. Many do not have typing skills or have poor dexterity after surgery. English is a second language for many and the nurse noted that many of his patients are not ‘readers’. He commented, “*Most of our patient’s are visual learners, it’s really the family who does a lot of reading and research. The video seemed to be what the patients enjoyed the most.*”

### ***Future directions***

Work is underway to develop a clinic department website which is being populated with excellent patient education materials. A limitation of the site is that although open to patients, material cannot be tailored for individuals. A major advantage of PEPTalk, from the nurse's perspective, is that PEPTalk provides tailored information that meets patient's needs at a particular point in time. Ideally, a link would be created from the department website to PEPTalk.

## **Interview with the Director, Knowledge Support Services, Centre for Effective Practice**

### *Experience with PEPTalk*

The Knowledge Support Services Director is responsible for the development of education programs for doctors, nurse practitioners, pharmacists and allied health professionals. She confirmed that patients and clinicians are overwhelmed by the amount of health information on the Internet. Patients are confused by the conflicting information they retrieve and consequently, bring what they find to their family doctor. She noted that, *“Physicians are faced with a patient coming in with stacks of paper from the Internet and not having time to sit down and go through everything with the patient. So, there’s a gap with what’s out there and a need for some type of criteria to assess content information.” There is no formal mechanism that I know of in place for the patient to know whether the information he looked at is trusted or researched.”*

Clinicians themselves are also bombarded with information. Their issues are similar to those reported by patients. They regularly receive health information tools and programs, often developed in isolation from each other. Compounding the situation are education silos; chronic disease information and programs often do not connect. For example, information developed for patients with diabetes does not connect with information on cardiovascular issues, although clinically the two health problems frequently present together. There is a real need for chronic disease management information such as quitting smoking, healthy eating, exercise guidelines; the type of information on PEPTalk. Another problem that clinicians face is matching materials

to the patient's literacy level. Either materials are too complex or patients report that they want more detailed, research-based resources. The issue is not a lack of health material, it is disseminating it in a user-friendly way. *“That's why we are excited about PEPTalk, it's a place that meets all those needs, the provider's need to give patient education, the way that information has been embedded, it's one stop shopping for the patient, and they know it's good material.”*

### ***Barriers and challenges***

While the concept is sound, further work needs to be done on the interface and the navigation process needs to be simplified. It is essential that technical issues regarding access are resolved. English as a second language is a major issue for their client population. The team services a very diverse community; resources are required in French, Mandarin, Cantonese, Punjabi, Portuguese, Spanish and Aboriginal languages. Recent work with First Nations groups indicates that this is a very spoken word culture, and the Centre had some success translating written material into MP3 files.

### ***Future directions***

Physicians and educators at the Centre definitely want to continue using PEPTalk. As the system rolls out a key issue will be to establish criteria for adding materials to the database. Volume and quality management will be important. Establishing a review board that would oversee the addition of new materials and check that information remains current and is evidence-based, will be key to ongoing success of the system.

## **Interview with community researcher**

### ***Experiences with PEPTalk***

Community health staff and members of the KO First Nations community partners were given access to PEPTalk for the project. The KORI researcher oriented them to PEPTalk and

facilitated access to the site. A recent survey had been conducted with First Nations communities in Northern Ontario that confirmed that there is a need for online health information resources for community members, particularly on topics such as mental health and diabetes and youth-oriented health material. Mental health councilors and lay people, for example, are seeking access to reliable health information. They do not find lecturing a helpful approach and prefer to give clinic attendees print information that they can take home and read. The same applies to families. *“I’m really pleased that that’s part of PEPTalk and the survey, family wellness, and how it can help your family. That’s really a central thing to First Nations people.”*

### ***Barriers and challenges***

A number of barriers to successful use of PEPTalk were identified. Some community members have limited computer skills such as accessing the Internet and keyboarding. Searching for health topics indexed by medical terminology, when English is not your first language, is a frustrating experience. The suggestion was made to set up an index of topics where users could click and select. The login process was identified as a barrier, partly for technical reasons, and also because it adds a step to accessing the site. The login and the issue of open access to information was also raised. The First Nations tradition is one of openness and sharing of information. Participants can understand the rationale for security and privacy for an individual’s personal health information account on PEPTalk, however they wondered about the possibility of opening access to the library of materials on PEPTalk. Another issue is that community members like to print materials. This supports the need for printer-friendly design of text pages on PEPTalk. Another major issue was video access: most participants the researcher spoke with had not been able to download the videos or could not be bothered because of the slow Internet speed; an issue they grapple with on their own website.

### ***Future directions***

The coordinator commented, “*It’s [PEPTalk] been a great value to us and to the lay person in the community.*” Ongoing access would be useful and marketing or information tools on PEPTalk, such as handouts and posters would be useful.

### **Focus group interviews with community staff: SCH**

A workshop and focus group interview was held at St. Christopher House with seven personal support workers (PSWs) and the program coordinator. The PSWs provide in-home care with activities of daily living to community members. The purpose of the session was to demonstrate PEPTalk and obtain feedback on site design and utility.

The response to the website was positive from all participants. They routinely search the Internet for personal and professional health related reasons and are overwhelmed by the volume of content retrieved and have difficulty interpreting results. They identified three ways that PEPTalk could be useful. Most importantly, PEPTalk could be a resource to support the care they provide to their clients. While all PSWs complete basic training, there is a need for ongoing access to resources for patient care and symptom management. The participants visualized accessing a SCH folder on PEPTalk from their own homes and perhaps from a client’s home, to get answers to questions that arise regarding client care and for ongoing professional development. The participants made several suggestions regarding content development for the website. These included: safe medication administration, falls prevention, choking prevention, range of motion exercises and health promotion content related to diet and activity. It was noted that content needs to be aligned with the PSW scope of practice; they are not allowed to give health advice to their clients, the focus would be enhancing their learning so that they can provide safe, quality care. The second way PEPTalk could be used was as a resource for their clients on basic health promotion activities. The participants said they would print resources for their clients since most were elderly and do not have a computer in the home.

### ***Barriers and challenges***

The majority of the PSWs' clients have fairly basic literacy levels and English is their second or third language. The participants were very satisfied that the materials they accessed on PEPTalk were presented in plain language, that the page design was clear and uncluttered. One participant commented, *"Language is an issue for us...that will not change quickly. That's very important. I do everything for clear language and this is clear and straight to the point...not too much, not too crowded and hard to read. I think seniors who could read – this is good."* Adding material to the site, as it develops, in other languages such as Portuguese, was identified as an important next step. Another key aspect that was raised was quality assurance. Participants said they had confidence in the materials posted on PEPTalk because they had been validated by local clinicians; reliability of information was seen as critical for patient safety and liability reasons. The factors identified by participants such as easy Internet access, clear language, simple page design and graphics and trust in the health materials presented online will potentially contribute to users' ability to access and comprehend health topics and support health literacy.

### ***Future directions***

An interview was conducted with the program coordinator who confirmed the need for a resource such as PEPTalk. Program facilitators at SCH often need to share health information at workshops or in their newsletters and it is critical that they use reliable, accurate information. Friendly visitors, SCH volunteers, sometimes ask for health information for the person they are visiting; that information must be validated. Further, staff, while their role is not to offer health information to clients, need information to ensure quality care. Funding is expected shortly for the Centre that will enable SCH to expand their computer resource area. SCH's goal is to improve computer services and training for seniors and others attending SCH. Because many community members do not have strong literacy skills, English is their second or third language, and many do not have computer or Internet skills, it has become clear through the project that an information facilitator or broker is needed to support PEPTalk integration. A staff person would work in the computer area to help users logon to PEPTalk, navigate the site, print information

and help them read material retrieved. The content areas that would be of most interest relate to health promotion: exercise, fitness, nutrition and preparing healthy food.

## **DISCUSSION**

Three diverse sites participated in the implementation and evaluation of online health information tools: patients and clinicians from a Family health team and clinic in a large urban centre, community members from a social support agency in an urban centre and community members and health providers from First Nations communities in Northern Ontario. Three models of website access were explored: Patients from the Family Health team and clinic were prescribed 'tailored' health information by their doctor or nurse. Community participants were directed to tools that were appropriate for their clients/members and their access to the site was facilitated through a community researcher. A multi-method data collection approach was used that included surveys with open ended items and interviews with clinicians and community staff.

One of the project objectives was to examine patient, community member and clinician website usage. Results were mixed. Of the 87 patients who were referred by physicians to PEPTalk, just 29 (33%) logged onto the website. Those logging onto PEPTalk accessed on average 3 items (SD 4.9), however the number of items accessed ranged from 0 to 20. Interview results with physicians suggest that patients appear keen to use PEPTalk in the office, however, when they get home, they get busy with other activities and they forget or do not bother to visit the site. As one physician commented, PEPTalk requires commitment; it requires the patient to participate actively in the education process. It is possible that the requirement for action, which includes logging onto the site, setting up an account and accessing materials is too demanding for many patients.

Technical barriers likely reduced the number of patients who visited the site. Four patients contacted the help desk to report technical problems with the site: they could not login or the site was not available. The project team also experienced site access problems on occasion. These technical problems likely had an impact on the number of people who participated in the

study and on the number of PEPTalk materials they accessed. PEPTalk is an experimental system that, while having undergone extensive design and engineering, nonetheless had some reliability issues. Most of these were related to how the server software functions, and the relative stability of this software over time. During the course of our study the system went down several times, resulting in diagnostic testing that led to the discovery of a memory leak in the system. While efforts were made to correct this problem, and the project team was diligent in monitoring the situation, there was a need to restart the server when problems arose.

Other issues with the system were discovered during the process of creating new clinical content packages for the study. This includes the workflow associated with uploading content, adding new clinics, and account creation. The project team has since embarked on an extensive re-engineering of the system, based largely on the results of this study, in order to simplify aspects of the system and to increase its reliability.

Community members at SCH and the KORI communities used a different approach that that used by patients. These participants were given a demonstration or one-to-one assistance to get onto the site; individual accounts were not created for these users. This approach worked well as beginning website users received the support they needed for their initial experience.

Patient, community member and clinician satisfaction was measured through surveys and interviews. The mean score for the total PHWSUQ (website satisfaction survey) for patients was 40.4 (SD4/7) out of a possible 50 and scores ranged from 33 to 48, indicating that most patients were very satisfied with PEPTalk. The mean score for KORI PEPTalk users was 38.4 (SD 4.5) and scores ranged from 32 to 45, indicating a moderately satisfactory experience. Participants from all sites found the information presented on PEPTalk useful and relevant and they were very confident in the quality of materials. While results for most survey items were similar, they differed significantly for the two groups in regard to three items: *“The overall appearance of the site makes it easy to use”*, *“Overall I found it easy to learn to use this website,”* and, *“This information on the website will help me maintain better health habits.”* One demographic variable where the two groups differed was educational level. All patients in this study had a high school (45%) or college/university (55%) education. Most participants from the KORI site

had a grade school education (62%), the remainder had completed high school except for one college/university graduate.

Educational status might have influenced users' abilities to navigate the site and has implications for improving the site design and navigation process; a finding that is supported by the interview results. Cultural factors may have influenced satisfaction scores as well. Participants gave feedback regarding the KNET breast cancer website indicating that the website would be most effective if integrated with face-to-face community health promotion activities. The mean score for the PHWSUQ for the community agency personal support workers was 48 out of 50. That very high satisfaction score was explained in the focus group and reflects the keen interest this group has in having access to reliable health information for own professional development to support client care. Further, this group had a demonstration and support in accessing PEPTalk, an important factor that likely influenced satisfaction scores.

Patient self-efficacy and health literacy regarding disease management and health behaviour change was measured using items on the PHWSUQ. All groups reported they had gained knowledge regarding health by using PEPTalk resources. The mean score for the item, "*The website improved my knowledge about health,*" had a mean score of 4.2 out of a possible 5 for KO participants, 3.8 for patients and 5 for community care providers. Nine of the eleven patients in the study gave an example of something they were doing that was new or different after using PEPTalk. They noted that the site helped in three ways: it provided new information, it provided ongoing access or the opportunity to review reliable information, and the site would act as a reminder or incentive to try a new health promoting behaviour. Eleven out of 15 respondents from the KO community gave examples of ways they would use PEPTalk. While some information was going to be used for self-care, several examples were given regarding sharing information with family, community members or clients in the case of health councilors.

Three major themes were identified from the quantitative and qualitative data collected from the three sites. These were: Valid, reliable access to online health information is critical, there is an emerging role of a knowledge broker and a learner-centered focus regarding design, technology and content is essential.

## **Valid, reliable access to health information is critical**

All participants, including those who had completed college/university noted that they are overwhelmed when retrieving Internet-based health information and have difficulty judging and interpreting material. Tailored, online, reliable, validated health information has value and potential; this message was heard consistently from patients, community members, clinicians and community staff. The issue is not the lack of health information, it is one of making manageable, relevant information available in a user-friendly way. The results, supported by other studies, indicate there is a definite need for reliable, quality, evidence-based health information, housed in a way that makes access simple and easy, similar to that offered through sites such as PEPTalk (Dart, 2008). Participants were very positive that health information was housed in one place, on PEPTalk, and they had a high level of confidence in the materials because the information had been vetted by local clinicians and selected for them by their clinician.

A key issue to address in the ongoing development of these sites is to ensure that a quality assurance system is maintained. Establishing a review board to oversee the addition of new materials and checking that information remains current and is evidence-based, will be key to ongoing success of the system. Regarding website design, it is essential to establish site credentials on the site home page, provide information on the site sponsor/developer, site purpose and outline the quality assurance process.

## **Emerging role of the knowledge broker**

While the overall response to PEPTalk was positive for those who accessed the site, uptake of the site was less than expected and likely requires more skills, time and commitment than some participants have or wish to expend. It became apparent during the PEPTalk implementation at the various sites that the role of facilitator or information go-between is needed. While emerging tools such as PEPTalk can be very useful in bridging the health literacy gap, it is critical that we do not put another barrier, technology, in the way for patients and community members. Further, it is important not to place the burden of introducing new

technology on an already busy clinician or staff person. The role of facilitator should not be added to an existing role, it needs to be given to someone who has good communication and teaching skills and time to support new system users. This person, situated at the family health practice or clinic setting or community organization would provide computer/Internet access, help users get on to the system and navigate, print materials and offer technical and other support. Providing both computers and staff support at community agencies would help organizations support health literacy for those who do not have access to hardware at home. This recommendation is supported by recent studies regarding the value of mediated access to verifiable health information (Bryan 2008). Further, it will be important for clinicians and health providers not to simply ‘hand the patient over’ to sites like PEPTalk believing that the health education piece has been addressed. The provider’s role regarding interpretation, discussion and follow-up will remain essential.

### **Learner-centred focus is essential**

Learners’ needs and characteristics should continue to guide design, technology and content choices. Participants in this study stressed the need for simple, easy-to-read, easy-to-print materials for the majority of users, however there is an emerging need for more complex material for high literacy users. As PEPTalk and similar sites develop, it will be important to ensure that new materials are written for the lay population and that complex, clinician-oriented materials do not trickle onto the site. Participants preferred pages that opened directly from PEPTalk; they disliked links to pdf files. Future development should include converting some text materials to picture rich aids as the literature suggests that printed text is the least effective means of communicating with patients.(Schwarzenberg, 2007) Ongoing evaluation with users is essential and will help to determine if their needs are being met.

Some of the findings of this study have already been implemented by KORI to improve not only their own website but the other health websites that are hosted by Keewatinook Okimakanak. Survey participants recognized that the Breast Cancer Foundation, Ontario chapter website is an effective portal to access current information on prevention and treatment. However, there was a strong indication that KORI should be posting original, locally developed

material to the website. In response, community stories have been added to the website to convey health information. In addition, KO participants indicated that they wanted to see the Breast Cancer Awareness website become more interactive. KO is seeking funding to facilitate a series of peer to peer counseling online circles for breast cancer survivors and those living with cancer in remote and isolated First Nations communities in the Northwestern Ontario. These peer to peer sessions will be hosted in Oji-Cree and Cree. The KO research team also recommends engaging participants in follow-up video conference workshops to discuss PEPTalk resources. It is possible that the web-based resources, supported by follow-up discussions, would improve the effectiveness of web resources in affecting health behaviour change.

Our second community partner, St. Christopher House, is committed to ongoing use of PEPTalk by implementing an information support person model. A staff member would help community staff and members with computer/Internet access, help users get on to the system and navigate, print and interpret materials. SCH has applied for Ministry funding to support the project. Further research is needed regarding the role of the health website mediator to support those with low computer/Internet or literacy skills. Our third partner, the Centre for Effective Practice is interested in offering PEPTalk access to all their clinicians and patients. It will be important to continue the research program initiated with this study to determine what can be done to encourage the initial website visit and to identify the processes and structures needed to encourage repeat visits.

### **Study limitations**

It should be noted that the results generated from qualitative data collection methods such as the interviews used in this study are not intended to be generalized. Further, the study's sample was relatively small and self-selected and may not be representative of the larger population of community members and staff. It should also be recalled that participants in this study had some familiarity with the Internet. PEPTalk has not been tested with Internet novices. A further limitation is that self report measures were used to measure patients' knowledge gains. While self report data tends to over-estimate participant activity, there is evidence that 'commitment to change' statements can be predictive of actual professional behaviour change;

that self report data can be a proxy for an objective measure of change. Indeed, by creating these statements, the participant may be more likely to actually make a change in practice (Wakefield et al., 2003). Further, objectively evaluating behavioural change in participants who use online health education materials is a challenge. Many of the tools developed to measure change in behaviour have not been sufficiently tested for the online environment (Ahearn, Kreslake & Phalen, 2006).

The research design used in this study may be described as triangulated as both survey and interview/focus group methods were used. These methods provided a very comprehensive picture of 'vetted' online health information from both the community member and clinician/community facilitator's perspectives. By combining methods, the researchers were able to add depth and breadth to understanding the phenomenon under study. Several areas for future research were identified during the study. These include examining the role of an on-site information broker, exploring patient-related barriers to website uptake and examining the best mix of text, video and sound files to support patient learning.

## **CONCLUSION**

There was a strong level of agreement in the issues identified by staff and community participants. The key issue identified is the difficulty finding reliable, comprehensible health information on the Internet. English literacy, computer literacy and access to a computer with Internet were identified as key factors that further compound the difficulty in conducting a fruitful search. Information that is retrieved needs to be presented in clear, plain language and supported by meaningful graphics where appropriate. Health information needs to be presented in languages and a cultural context familiar to the user.

These results strongly support the development of websites such as PEPTalk that house basic health information that has been validated by clinicians and where that validation is apparent to the user. This tool would simplify the search process by reducing the complexity of the search process and it would give the user confidence in the materials retrieved. Simple

evaluation tools that teach users how to evaluate websites and information retrieved could be added to the site to enhance health literacy skills.

This form of public health education has significant implications for better utilization of scarce healthcare resources and the empowerment of Canadians to take active roles in managing their health. We anticipate that Internet access and the ability to customize health materials will open up learning opportunities for all Canadians but in particular for those who face traditional barriers related to literacy, education and geography.

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## **APPENDIX**

### **APPENDIX A Surveys and interview guides**

#### **1) Keewaytinook Okimakanak participant survey\***

**\* minor adaptations were made in wording for the Family health team patient version and SCH community staff and member version.**

#### **INTERNET EXPERIENCE SURVEY**

##### **Purpose:**

We want to find out about people's Internet skills, and their use of the Internet to access health information. If they do access online health information, what is their impression of the KNET health information websites?

##### **Please complete the following two-part survey**

**Part 1:** You will be asked for information about your experience in general with the Internet and finding health information on the Internet.

**Part 2:** You will be asked about your experience with the KNET breast cancer website.



**PART 2: KNET BREAST CANCER WEBSITE ( Perceived Health Web Site Usability Questionnaire (PHWSUQ))**

**This questionnaire examines your satisfaction with the KNET breast cancer website. Please circle the number that matches your experience.**

1. It is easy to find information on the KNET health information website  
**Strongly disagree   1   2   3   4   5   6   7   Strongly agree**
2. It is easy to read the information provided  
**Strongly disagree   1   2   3   4   5   6   7   Strongly agree**
3. It is easy to use the video provided  
**Strongly disagree   1   2   3   4   5   6   7   Strongly agree**
4. The overall appearance of the site makes it easy to use  
**Strongly disagree   1   2   3   4   5   6   7   Strongly agree**
5. The information I found on the KNET website was relevant to my health at this time  
**Strongly disagree   1   2   3   4   5   6   7   Strongly agree**
6. The information presented on the KNET health information website is useful  
**Strongly disagree   1   2   3   4   5   6   7   Strongly agree**
7. I have confidence in the material presented on the KNET health information website  
**Strongly disagree   1   2   3   4   5   6   7   Strongly agree**
8. Overall I found it easy to learn to use the KNET health information website  
**Strongly disagree   1   2   3   4   5   6   7   Strongly agree**
9. The KNET health information website will improve my knowledge about health  
**Strongly disagree   1   2   3   4   5   6   7   Strongly agree**
10. This information on the KNET health information website will help me maintain better health habits  
**Strongly disagree   1   2   3   4   5   6   7   Strongly agree**
11. I would recommend the KNET health information website to others who are seeking reliable health information  
**Strongly disagree   1   2   3   4   5   6   7   Strongly agree**

12. What parts of the KNET health information website will be most helpful to you?
13. What parts will not be useful or difficult to use?
14. What changes would you recommend?
15. After using PEPTalk, I can provide an example of something new or different that I am doing, or plan to do, regarding my personal health or my family's health.  
Example:
16. How will PEPTalk help you understand your health and live a healthy lifestyle?

## **2) Clinician Website Satisfaction Interview guide\***

**\* The interview guide was tailored for each participant group**

1. How long have you been using PEPTalk?
2. How many patients have you referred to PEPTalk since January?
3. Can you tell me how you use PEPTalk in your clinical visit... where and how does the referral happen?
4. How has that worked? Is there part of the process that is clumsy/difficult for you?  
What needs to happen to make it a better /simpler fit?
5. You are prescribing using paper... how is that working? Could you ever anticipate prescribing online?
6. What has been the reaction from your patients? How are you selecting those to refer? Who are the keeners? Have you had any repeat users?
7. For those patients who are not interested or reluctant... what seems to be the barrier?
8. What needs to happen to make it easier/better for your patients?
9. Do you find PEPTalk useful? Does it add value beyond what is currently available through pamphlets and health organization websites? What could be done to make it more useful?
10. What content has been particularly helpful so far? What content needs to be added?
11. Do you think having access to this kind of information through the Internet will improve patients' health? If yes, can you give me an example of how it will help? If not, please elaborate.
12. It is very important that PEPTalk is easy to use and worth visiting. What recommendations do you have? (design, content, process etc....)

13. Is there anything else you'd like to add?

### **Community Leader Interview guide**

1. What is your role in relation to the KNET website and the health information posted there?
2. In your experience, do many people in your community like to use the Internet to find health information? What are some of the barriers to using the Internet?
3. What has been your experience with PEPTalk? Your community members response? Are the resources useful?
4. How are people advised that health information is available on the PEPTalk site?
5. What have you found helpful? Not helpful?
6. What have been some of the supports to using the site? Barriers?
7. What do you think needs to change to improve the site? To improve site usage?
8. What recommendations would you have as we try to learn more about making PEPTalk a useful, easy place to go for health information?
9. Would your community like to continue accessing a resource like PEPTalk?
10. Is there anything you'd like to add to what we've talked about?

### **Clinician Interview guide: needs assessment focus group interviews**

- 1) Do you utilize patient education/resources in your practice?
- 2) When a patient is newly diagnosed with diabetes or another illness, what process do you use to educate the patient? What materials/resources are used?
- 3) What works well with the current system of patient education? What are the limitations/problems with the current system?
- 4) Do you ever refer your patients to the Internet for health resources? If so, what sites do you typically refer to and for what kinds of information? Do you 'vet' the sites before sending them there?
- 5) During what percentage of your clinical encounters does a patient present you with information from the Internet? What is the general quality of the information presented? When a patient presents with Internet information, what impact does that have on the clinical encounter?
- 6) What degree of digital/information literacy in general would you say your patients have? What percentage look for health information on the Internet? What is their response to what they find? Do you have programs you can refer a patient to, to help boost their health literacy, to help them interpret what they've found?
- 7) PEPTalk, the project that is currently underway, takes existing patient education materials, developed by local clinicians and reformats them for the Internet. The clinician then "prescribes" the appropriate information for the right patient, at the right time. The patient can view information via the Internet or it can be printed. What is your response to that system?
- 8) What are your concerns about a system such as PEPTalk?

- 9) If you were to implement something like PEPTalk, what would be some of the barriers to this process? What needs to be done to make that a simple and efficient process from your perspective?
- 10) If you adopted such a system, what would be your concerns regarding the impact on the clinical encounter?
- 11) If you were to adopt a system like PEPTalk, what training or orientation would you need and how would you like to receive that training?
- 12) Are there any other comments or questions you'd like to raise?