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Information Needs of Prostate Cancer Patients Post-Treatment: Does Tailored Information Help?

Ph.D. Thesis Seminar

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1. Introduction

Prostate cancer is the most commonly diagnosed cancer in Canadian men. Both the disease and its treatments can have significant effects on health-related quality of life (HRQOL), causing pain, low energy, incontinence, erectile dysfunction and bowel problems. Men participating in treatment decisions or coping with symptoms after treatment often have high information needs.

An increasing number of prostate cancer patients are seeking information outside of clinical interviews via the Internet, however most online sources of health information do not adapt to individual differences and many men report difficulty finding relevant information.

In this dissertation I will address the problem of how relevant information might be delivered to prostate cancer patients online, focusing on individual differences that may predict different information needs or search strategies, such as health status, behavioural style, literacy, numeracy, sociodemographic and geographic factors. Which factors influence how information about prostate cancer, treatment options and associated HRQOL should be presented to men living with prostate cancer? In particular, can information be tailored so that it best meets the needs of a particular person in a particular medical context?

This research is motivated by the concern that standardized ("one size fits all") content and presentation do not readily adapt to the personal capabilities, preferences and styles of different information seekers. Thus, in the case of prostate cancer, the work of finding relevant information shifts to men and their families. I expect that appropriate tailoring of information will increase its uptake, perceived relevance, and acceptability, while also encouraging better coping with post-treatment symptoms, leading to greater overall satisfaction with health outcomes.

Tailoring of information is especially well-suited to the inherent flexibility of the Web and the growing rise of user-generated content and online personalization.

The remainder of this document will describe my research plan for studying how tailored information might be used in the context of information-seeking by prostate cancer patients post treatment. In addition to presenting a plan for future work, later sections of this document will also describe the progress made thus far, including the research literature reviewed, the theoretical framework that has been developed, and the results that have been obtained from an extensive interview study.

2. Objectives

2.1 Primary Objective

The primary objective of this research program is to examine whether individual differences among men with prostate cancer influence their satisfaction ratings of Web-based information on the topic of Health-Related Quality of Life after prostate cancer treatment. Individual differences will be assessed across a variety of constructs with three areas of greatest interest: (1) health state (symptoms), (2) behavioural or coping style (monitoring/blunting, Miller 1987) and (3) education factors (health literacy and numeracy.)

Web-based information will vary according to both content and presentation. It is hypothesized that health state will influence satisfaction with information content, behavioural style will influence satisfaction with information presentation, and education factors will influence both.

2.2 Secondary Objectives

Additional outcome measures besides satisfaction ratings will be considered, including *self-efficacy for symptom control* (Campbell et. al. 2004), anxiety, depression, social support, time spent on Websites, number of clicks on hyperlinks, and drop-out rates within longitudinal studies.

Further individual differences will also be examined for possible effects on outcomes. Additional differentiating factors include users' comorbidity, disease history, age, communication preferences (Parker et. al. 2002), stage of change (Prochaska et. al. 1992), Health Locus of Control (Wallston et. al. 1978), socioeconomic status, interest in complementary and alternative medicine, interest in base rate statistics and/or stories from other men and geographic factors such as access to health care providers, specialists, support groups, Web access and location (home, work, library, via family member, physician's office).

Note that in this context, disease history means treatment(s) received, cancer stage(s) as a function of time, PSA as a function of time and Gleason score. (For explanations of medical terms used, please see Appendix B: Glossary of Medical Terms.)

3. Fundamentals/Principles

3.1 Prostate Cancer and Health-Related Quality of Life (HRQOL)

Approximately one in every six North American men will be diagnosed with prostate cancer in his lifetime (<http://mayoclinic.com>). Prostate cancer is the most commonly diagnosed cancer for Canadian men (<http://healthyontario.com>) and the risk increases with age. For most people, prostate cancer is a chronic disease.

Most prostate cancer patients are more likely to die with the disease than from it (Jamnicky & Nam 2003). Thus, a major thrust of prostate cancer care involves helping men cope with the HRQOL effects of the disease and its treatments.

HRQOL is a multidimensional construct that incorporates various aspects about a person's health state including factors such as general health, physical function, physical symptoms & toxicity, emotional function, cognitive function, role function, social well being and function, sexual function and spiritual/existential issues (Walters 2002). Measurements of HRQOL are conducted via indices where individual items represent different factors and the resultant utility score on the interval [0,1] represents overall HRQOL (McDowell & Newell 1996).

Multiple studies have shown that the incorporation of HRQOL information in the clinical setting increases patient satisfaction and improves the level of care (Detmar et. al. 2000, Spyt et. al. 2002, Kettis Lindblad et. al. 2002, Taenzer et. al. 2000, Montazeri et. al. 2003, Walker et. al. 2003). When HRQOL data are explicitly used, such as when a questionnaire is administered prior to a visit, patient-physician communication is improved and more HRQOL factors are addressed in the clinical interview (Taenzer et. al. 2000). Additionally, providing patients with information about cancer and HRQOL can reduce depression (Schofield et. al. 2003, Fallowfield et. al. 2002). Unfortunately, routine use of HRQOL data in clinical practice is rare (Kettis Lindblad et. al. 2002).

Prostate cancer and its treatments can have significant impact on a person's HRQOL, causing anxiety, emotional distress and problems with urinary, bowel and sexual function. Unless cancer is detected early through screening, a diagnosis of prostate cancer usually occurs when a man is already experiencing symptoms such as urinary difficulties or pain (Jamnicky & Nam 2003). Once the cancer has been diagnosed, there are a number of options for treatment.

The treatments for prostate cancer vary in their efficacy at various stages of cancer as well as their HRQOL side effects. It is not uncommon for prostate cancer patients to ultimately receive more than one treatment, for example, surgery followed by radiation or hormone therapy.

Table 1: Common Prostate Cancer Treatments

Treatment	Description/Comments	Side Effects/Negatives
None		
Watchful Waiting	No action taken; cancer is observed to see how slowly or quickly it is progressing.	Higher risk of metastases; not a cure.
Hormone Therapy		
Hormone Injections and/or Pills	Drugs are used to moderate testosterone production and/or action.	Hot flashes; loss of libido; sexual dysfunction; fatigue; weakness; long-term risk of osteoporosis and anemia; injections

		require regular doctor's visits; not a cure.
Radiation Therapy		
Brachytherapy	Radioactive seeds are implanted in prostate; in some health care systems, only offered to patients with less aggressive cancer.	Fatigue; urinary symptoms; bowel symptoms; erectile dysfunction; requires local anesthesia.
Beam, Conformal and Intensity Modulated Radiotherapy	Radiation is directed at the prostate, typically for 10-15 minutes a day, 5 days a week for 7-8 weeks.	Fatigue; urinary symptoms; bowel symptoms; erectile dysfunction; requires many clinic visits.
Surgery		
Radical Prostatectomy	Prostate is surgically removed; nerve-sparing surgery is an option for some patients/surgeons.	Invasive; requires general anesthesia, up to 3 weeks of catheterization and 6 weeks to recover fully from surgery; urinary incontinence; erectile dysfunction.

(adapted from Jamnicky & Nam 2003)

In order to meaningfully assess HRQOL in prostate cancer patients, the Patient-Oriented Prostate Utility Scale (PORPUS) was developed (Krahn et. al., 2000). This instrument captures HRQOL of prostate cancer patients post-treatment via ten items. Five items are common to most cancers: pain; energy; support from family & friends; communication with doctor and emotional well-being. The other five are specific to prostate cancer: urinary frequency; leaking; sexual function; sexual drive and bowel function. The reliability, validity and responsiveness of the scale have been demonstrated in prostate cancer patients (Krahn et. al. 2000, 2003, 2005).

3.2 Prostate Cancer Patients' Information Needs and the Internet

A diagnosis of prostate cancer generates high information needs. Over 50% of prostate cancer patients actively seek information about their disease (Hellawell et. al. 2000, Sutherland et. al. 1989). High levels of information seeking have been shown to be associated with effective coping strategies for prostate cancer (Ben-Tovim et. al. 2002). Information about their condition helps people with cancer to gain a sense of control, reduce anxiety, create realistic expectations, promote self-care and participation, and generate feelings of safety and security. Further, provision of information can have beneficial effects on compliance, patient satisfaction, clinical outcomes, and quality of life (Jefford et. al. 2002, Broom 2005).

However, there is evidence that prostate cancer patients' information needs are not being met. Men who are experiencing side effects of treatment have few avenues to learn more about their symptoms, about what they can do to alleviate their symptoms and about whether or not their experiences are normal (Jefford et. al. 2002, Monnier 2002, Steginga et. al. 2001, Echlin et. al. 2002, Visser et. al. 2003, Boberg et. al. 2003). Furthermore, prostate cancer patients and their health care providers may have markedly different conceptualizations of patients' information needs (Capirci 2005) and patients may find it difficult to obtain the information they want and need during clinical visits (Rozmovits & Ziebland 2004). Information from other

patients who have “been there and done that” can be particularly useful to patients for setting their minds at ease about what is and is not normal, and about what they might expect in the course of their disease experience (Rozmovits & Ziebland 2004, Broom 2005).

There is a growing reliance on the Internet for health information (Horrigan & Rainie 2002, Ziebland 2004). This trend, observed across age and gender groups (Fox & Rainie 2002), is both transforming and being transformed by the way cancer patients seek information and cope with their disease. There is evidence of a significant population of cancer patients on the Internet and a nontrivial proportion of prostate cancer patients use the Internet to help satisfy their information needs (Cumbo 2002, Sharp 1999, Pautler et. al. 2001, Hellawell et. al. 2000, Jones et. al. 2001, Junghans et. al. 2002, Peterson et. al. 2003, Monnier et. al. 2002, Ziebland et. al. 2004).

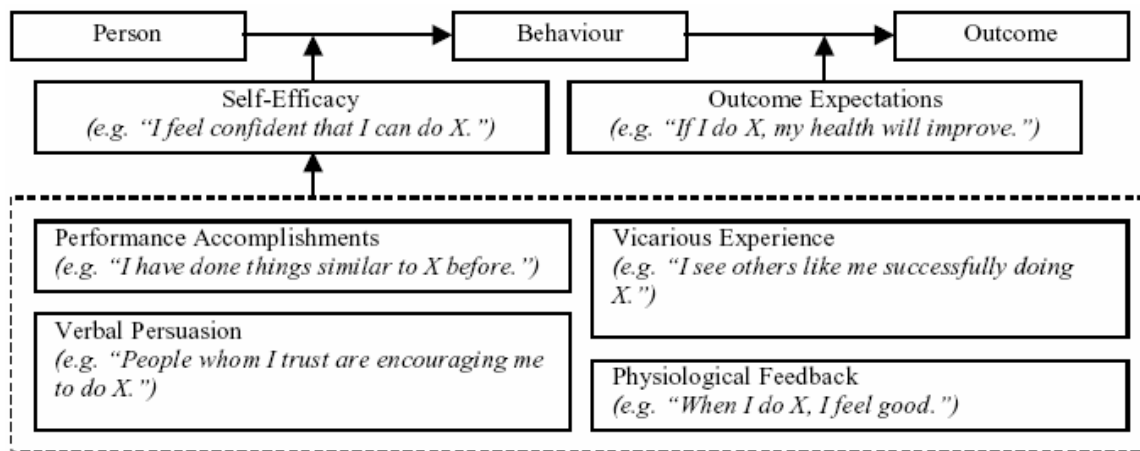
While there are valid concerns about the quality of information available (Eysenbach et. al. 2002, Broom 2005) and of information seeking leading to increased information needs (Feltwell & Rees 2004), overall, this can be considered to be a positive trend. Over 50% of patients who research their concerns on the Internet prior to appointments find that the ensuing discussions with their physician contribute to more constructive consultations (Boyer et. al. 2002).

Much of the information sought online about prostate cancer has to do with health outcomes of treatments, specifically life expectancy and HRQOL concerns such as incontinence and impotence (Ziebland 2004). While a great deal of such information exists online, there is evidence that patients have trouble finding information that is relevant to them. One study examining this issue found that of prostate cancer patients who have sought information online, 40% were not able to find the information desired (Buntrock 2004).

3.3 Self-Efficacy

Self-efficacy is defined as confidence in one’s ability to achieve a specific goal (Bandura 1997). Bandura’s Social Cognitive Theory (SCT) models self-efficacy as a predictor of behaviour and identifies four types of information sources that influence efficacy expectations:

Figure 1: Social Cognitive Theory (SCT) Model



(adapted from Allen 2004 and Bandura 1986)

Self-efficacy has been shown to be significantly associated with self-care (Allen 2004). In prostate cancer patients specifically, self-efficacy for symptom control has been shown to be positively associated with HRQOL (Campbell 2004).

Empirical evidence shows that self-efficacy is correlated with related constructs such as self-esteem, neuroticism (negative association), locus of control and mastery. (Judge 2002, Kempen et. al. 1997). However, “self-efficacy varies with tasks and behavioral challenges. In this way it is unlike constructs such as self-esteem that describe a general state of being,” (Clark & Dodge 1999) and self-efficacy has been shown to be mutable with respect to health goals (Kukafka et. al. 2002, McAuley et. al. 1999). In this research, among other goals, I aim to increase *self-efficacy for symptom control* in prostate cancer patients post-treatment.

3.4 Tailored Health Education Interventions

3.4.1 Health Education Intervention Goals

The goal of most health education interventions is to produce behavioural change. Typical goals include smoking cessation, exercise adherence and dietary modification. In this program, behavioural change is operationalized as any steps taken by a post-treatment prostate cancer patient with the goal of improving his HRQOL. Examples include making lifestyle improvements, discussing concerns with his doctor, seeking additional or alternative therapies and changing his thinking patterns or attitudes about his health status.

Theories of health behaviour, behavioural change and motivation include the Health Belief Model (Strecher et. al. 1986), the Theory of Planned Behavior (Ajzen 1991), the Health Action Process Approach (Schwarzer 1992), the Precaution Adoption Process Model (Weinstein 1988), the Goal Achievement Theory (Bagozzi 1992), and the Transtheoretical Model (TTM) (Prochaska et. al. 1992). It is the latter model that is

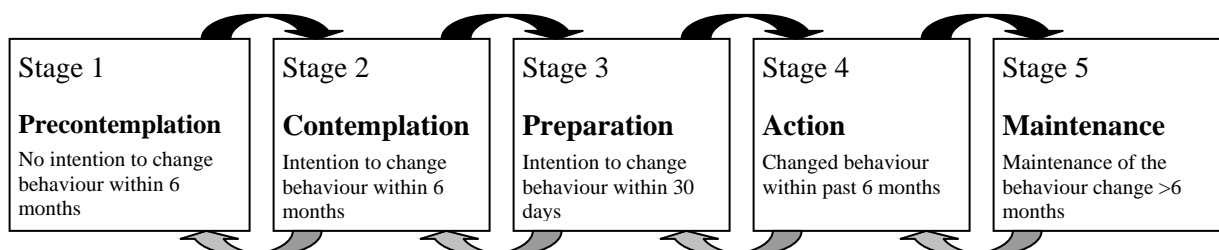
used as a framework for this research.

As described by De Vet et. al. (2005):

The stages of change concept from the Transtheoretical Model (TTM) (Prochaska et. al., 1992) has been widely used as a basis for planning health promotion interventions (Prochaska et. al., 1993; Naylor et. al., 1999), as an indicator for effects of health promotion interventions (Brug and Van Assema, 2000; Resnicow et. al., 2003) and to examine determinants of health behavior change (Brug et. al., 1997; Plotnikoff et. al., 2001; Ma et. al., 2002).

Prochaska et. al. (1992) modeled behaviour change as a series of five Stages of Change. During the process, people may occasionally move back rather than forward through the stages, but none of the stages will be skipped.

Figure 2: Transtheoretical Model (TTM)



(adapted from Prochaska et. al. 1992)

Within the TTM framework, positive health goals are achieved by moving forward through the five stages of change. In a study aimed at to identifying the determinants of forward stage movement, De Vet et. al. (2004) found that self-efficacy was an important determinant of forward stage movement for all four transitions.

3.4.2 Tailored Health Education

Tailoring is defined as the adaptation of information according to the needs, preferences and characteristics of the individual receiving the information (Bental et. al. 1999). Tailoring expands on targeting and personalization, in which information is adapted for subgroups or in which messages are injected with personal identifiers, respectively (De Vries & Brug 1999).

At minimum, an information tailoring system requires: (1) user profiles, (2) a message library, (3) an algorithm that filters messages according to user profiles, and (4) a channel for delivery of messages (De Vries & Brug 1999).

Empirical evidence shows that tailored messages are more likely to be read & remembered, rated as attention catching, saved, discussed with others and perceived as personally relevant (Kreuter & Wray 2003). Furthermore, tailored information is more likely to motivate behaviour change (Dijkstra & De Vries 1999, Strecher 1999). It has been suggested that this is because tailoring increases one's attention to the message because of increased perceived personal relevance (Dijkstra 2005).

When tailored information is not available, the lack of personally relevant information can cause frustration for a person navigating a path through a disease experience, including coping with the HRQOL effects of cancer treatment. Gould et. al. (2006) found in interviews with women with breast cancer that young women expressed dismay that much of the existing literature on breast cancer did not incorporate their individual concerns. A common theme was that, despite a wealth of information, "Nothing fit me."

As described in section 4.1, a similar theme emerged in interviews with prostate cancer patients. Many men expressed a desire for personally relevant information and some described frustration that their particular concerns remained unaddressed despite extensive searching and questioning.

Tailoring health information may include techniques such as adapting the content to the user's health state and adapting the language used in the messages to the user's Behavioural Style (Miller 1987) and levels of literacy, health literacy and numeracy.

3.5 Behavioural Style and Health Locus of Control

Miller's Behavioural Style Scale is predicated on the idea that people tend to cope with negative situations either by blunting or monitoring. Blunters avoid information and prefer not to think about their negative situation any more than necessary, while monitors aggressively seek out additional information (Miller 1987). The distinction between monitors and blunters is paralleled in the difference between the clichés, "Knowledge is power," and, "Ignorance is bliss."

Williams-Piehota et. al. (2005) demonstrated that for women at risk of breast cancer, adapting messages about the importance of mammography to receivers' behavioural style increased blunters' likelihood of obtaining a mammogram.

Health Locus of Control refers to whether people consider their health outcomes to be largely within their own control (internal HLC), within the control of others (powerful other HLC) or subject to chance, luck or fate (chance HLC) (Wallston et. al. 1978).

Although some researchers have theorized that Behavioural Style and Health Locus of Control have the same underlying construct, others have provided empirical evidence suggesting that they are independent concepts (Koo et. al. 2006).

3.6 Education, Literacy and Numeracy

Research concerning patients' use of information for decision-making and self-care abounds. Frequent areas of concern are those of literacy and health literacy. More recently, concerns about numeracy have arisen, particularly with respect to patient decision-making in the context of numerically-described risk (Montori & Rothman 2005, Woloshin et. al. 2001). All of these concerns address the same core issues: How well do patients

understand the information with which they are presented and how well can they use it to make informed decisions?

Peters et. al. (2006) showed in a series of four studies that people with varying levels of numeracy responded differently to framed decision-making scenarios and that these differences in responses were independent of general intelligence. The preponderance of numerical information surrounding topics in HRQOL and prostate cancer leads us to consider numeracy as an independent determinant of an individual's ability to effectively make use of existing online health resources.

Health numeracy has been operationalized by Golbeck et. al. (2005) as encompassing four distinct concepts:

Table 2: Health Numeracy

Concept	Attributes	Example(s) of Tasks
Basic health numeracy	<ul style="list-style-type: none"> ▪ basic skills to identify numbers ▪ make sense of quantitative data requiring no manipulation of numbers 	<ul style="list-style-type: none"> ▪ identifying the appropriate number of pills to take from a prescription bottle ▪ determining the date and time of a doctor's appointment ▪ using a phone book to find a clinic's phone number
Computational health numeracy	<ul style="list-style-type: none"> ▪ ability to count, quantify, compute, and otherwise use simple manipulation of numbers, quantities, items, or visual elements in a health context so as to function in everyday health situations 	<ul style="list-style-type: none"> ▪ determining net carbohydrates based on information on a nutritional label ▪ determining fees based on a sliding scale
Analytical health numeracy	<ul style="list-style-type: none"> ▪ ability to make sense of information, such as that presented in functional health numeracy ▪ also involves higher level concepts such as inference, estimation, proportions, percentages, frequencies, and equivalent situations ▪ often requires information to be pulled from multiple sources and in multiple formats 	<ul style="list-style-type: none"> ▪ determining whether cholesterol levels are within the normal range ▪ understanding basic graphs ▪ comparing benefits from various insurance policies or programs
Statistical health numeracy	<ul style="list-style-type: none"> ▪ understanding of basic biostatistics involving probability statements ▪ skills to compare information presented on different scales (probability, proportion, percent) ▪ ability to critically analyze quantitative health information such as life expectancy and risk ▪ understanding of statistical concepts such as randomization and a "blind" study 	<ul style="list-style-type: none"> ▪ determining preference of treatment based on probabilities of efficacy and side effects ▪ interpreting complex graphs of health information ▪ making decisions based on relative versus absolute risk

(adapted from Golbeck et. al. 2005)

3.6.1 Communicating Numerical Health Information

Brundage et. al. (2005) examined the responses of cancer patients, 29% of whom were men with prostate cancer, to text and graphical representations of HRQOL outcomes for two simplified theoretical cancer treatments. They found, unsurprisingly, that older participants and those with lower education levels had lower accuracy scores. They also discovered that simple linear graphical representations of mean HRQOL garnered the strongest preference ratings and accuracy scores across age and education levels.

These findings suggest that there may be an optimal "default" display for numerical HRQOL information in the context of cancer, although questions remain regarding the display of more complex information. This trial showed a negative preference for displays containing information about the distribution of HRQOL scores (namely, mean scores with error bars) and therefore raises questions about how best to display comparisons in situations where different choices or treatments result in wider variation of HRQOL outcomes.

Furthermore, when considering how and whether to display a patient's individual HRQOL score, we do not know whether it is harmful or helpful to show their score within the complexity of a distribution or simply to show it as above or below a mean value.

3.7 Web 2.0 and User-Generated Content

Web 2.0 is a term coined by Tim O'Reilly to describe a shift in the way the Web is used. O'Reilly operationalized the key attributes of Web 2.0 as:

Core Competencies of Web 2.0 Companies (O'Reilly 2005)

- * Services, not packaged software, with cost-effective scalability
- * Control over unique, hard-to-recreate data sources that get richer as more people use them
- * Trusting users as co-developers
- * Harnessing collective intelligence
- * Leveraging the long tail through customer self-service
- * Software above the level of a single device
- * Lightweight user interfaces, development models, AND business models

Of particular note to this research program – and moreover, to online health information in general – is the growing rise in flexible systems and user-generated content.

Kamel Boulos & Wheeler (2007) outline some of the implications of Web 2.0 for online health information, notably the sharing of information among health care consumers via online collaborative environments.

In this research, I hypothesize that men with prostate cancer will be motivated to share information online with other men, specifically, to recommend information sources to other men and make use of others' recommendations.

3.8 Recommender Systems

Recommender systems are computer-based systems that make use of characteristics of items within a particular class of interest and/or characteristics of individual users of the system in order to match users with items that are determined to be of potential interest to them. For example, Amazon (<http://www.amazon.com>) recommends items based on a user's browsing and buying history as well as the purchase patterns of other users.

Systems that rely exclusively on item characteristics are examples of pure *content-based filtering* whereas those that rely exclusively on user characteristics are examples of pure *collaborative filtering*. Systems that employ aspects of both techniques are known as *hybrid systems* (Yu et. al. 2004).

For example, a recommender system might aim to provide recommendations for movies that people might like. Under the *content-based filtering* model, the system might provide recommendations based on a user's defined preferences for movies of specific genres or with specific directors or actors. Under the *collaborative filtering* model, the system would note the movies that a user had rated highly; find other users who shared those preferences, and recommend other movies that had been rated highly by those other users. A *hybrid system* would combine aspects of both techniques, possibly seeking other users who prefer the same set of actors and directors and exploring movies they rated highly outside that set.

Adomavicius & Tuzhilin (2005) list the following distinctions:

Content-based recommendations: The user will be recommended items similar to the ones the user preferred in the past;

Collaborative recommendations: The user will be recommended items that people with similar tastes and preferences liked in the past;

Hybrid approaches: These methods combine collaborative and content-based methods.

4. Research To Date

This research will be undertaken in four studies, the first of which is described here.

4.1. Qualitative study - Interviews with patients (completed)

A preliminary study was conducted to assess the usability of a prototype Website for collecting HRQOL data online and to determine user needs for HRQOL information, user preferences for information tailoring and to generate hypotheses about the effects of an intervention involving tailored information about symptom control post-treatment.

Methods

30 patients with prostate cancer were recruited from three physicians' clinics at the Prostate Centre at Princess

Margaret Hospital, Toronto. One patient did not attend his appointment; 29 patients participated in 30-60 minute mixed methods sessions that involved filling out several questionnaires, interacting with the prototype Website and answering open-ended interview questions (see Appendix E for interview guide.) Interviews were recorded via shorthand.

Measurement instruments included two brief, ad hoc questionnaires and the Cancer Behavior Inventory v2.0 - Brief (CBI-B) (Merluzzi et. al. 2001), a validated index of cancer patients' coping efficacy. Semi-structured interviews addressed other multidimensional constructs such as user preferences about tailored information, information needs of prostate cancer patients, and preferences about information sources.

Interview transcripts were coded by the researcher, and themes were extracted according to principles of grounded theory (Glaser & Strauss 1967, Pope & Mays 1995, Patton 1990).

Results

Overall, participants had positive responses to the prototype. Some usability issues were identified through the study (see Appendix D); these issues will be addressed in future Website prototypes. Participants indicated that, overall, the prototype Website was easy to use and they would visit a site such as this on their own.

The CBI-B was used to assess change in coping efficacy before and after interacting with the prototype. However, many participants found one or more of the items confusing or irrelevant and results showed ceiling effects, indicating that this instrument is unsuitable for use with this population.

After interacting with the prototype, participants showed a statistically significant greater perceived need to seek further information outside of clinical interviews (95% CI 0.19-1.49, n=25). (See Appendix F for further results.) When asked to compare paper prototypes representing different types of information that might satisfy these needs, in general, participants' rankings suggest that information tailored according to users' HRQOL scores is slightly more likely to satisfy their information needs than non-tailored information.

Content analysis suggests the following salient themes: Patients value their doctors' advice highly, but sometimes find it difficult to get enough of their doctor's time to have all their questions answered and concerns addressed. Patients are interested in being kept up to date on prostate cancer research, especially if the research relates to them. Patients are generally interested in receiving information that is relevant and specific to them, but they have mixed opinions on whether normative feedback, in particular, is useful. Finally, some patients are high information seekers and may be frustrated about types or levels of information that are inaccessible to them, while others feel that too much information can be harmful to one's sense of well-being.

Table 2: Themes and Sample Comments from Interviews

Theme	Sample Comments
Patients weight physician's comments and	When deciding on a treatment, several participants asked

opinions heavily in decision-making and coping.	<p>their doctors, “What would you do if it were you?”</p> <p>“[S]itting down with Dr. -- and hearing, ‘Everything looks good,’ — that's the most reassuring.”</p> <p>“Anything I can find, I read it. But the doctor is the final answer. I get more questions from the sheets and then I talk to Dr. -- about them to get his ideas.”</p>
Patients may have trouble getting the information they desire during clinical interviews.	<p>“I think doctors are too busy to tell you everything you need to know.”</p> <p>“He [my doctor] doesn't know what I need to know.”</p>
Participants are interested in being aware of what research is being done in prostate cancer, especially if such research requires their submission of information.	<p>“I'd be interested in knowing what the researchers are doing with the information. It doesn't necessarily have to be for my benefit; I'm interested in helping others.”</p>
Participants would like information that addresses their issues and concerns specifically.	<p>“I would like to get feedback on specific things that affect me.”</p>
Some participants feel that normative feedback is useful.	<p>“After my operation, I need to know how I did, how I compare to other people.”</p> <p>“What I'd like to see is how I compare to what the expectation is for that patient. If I'm falling short, I need to do something.”</p> <p>“You do want to know how you're ranking in terms of everybody else. What's happening to you may be completely normal.”</p>
Other participants feel that normative feedback is not helpful, and may have negative effects.	<p>“I'd rather know [if I were doing poorly compared to others], but yeah, it would make me feel badly.”</p> <p>“That's not the kind of news you want to hear. I wouldn't want to hear that right off the bat. That would be the last thing I'd want to know.”</p> <p>“I don't think that comparison with a standard is helpful.”</p> <p>“Never tell men how bad it is. Don't lie to him, but the truth hurts and gets him more sick.”</p>
Some patients are very high information-seekers and feel that information helps them cope.	<p>“I want to learn what I've been on and everything regarding it.”</p> <p>“[I sought] general information, basically what's going to happen and what to expect. It helped me a hell of a lot, really calmed me down.”</p> <p>“I remember there was one Website where there was feedback from other men about their experiences. It's useful to see what the future holds.”</p>
Others feel that information can have negative effects.	<p>“Sometimes a lot of information is not good. It's good to have some information, but a lot can be depressing.”</p> <p>“[You should] reinforce the positive aspects. A lot of this Internet stuff is very frightening.”</p>
Some participants have been frustrated by their lack of success at finding the information they seek.	<p>“How long can I expect to go on this hormone therapy before I become refractory? I can't believe there are no stats.”</p> <p>“I haven't been able to get any information about my major concern: weight gain and changing fat distribution</p>

Discussion

The key finding from this study are that even among a relatively homogeneous patient population, strong differences arise in terms of desired information. Different men have different search strategies as well as different preferences for type, quantity and presentation of information. This leads us to the question: When it comes to prostate cancer and HRQOL information, does one size fit all? And if not, can we predict preferences for information content and presentation based on key individual characteristics?

5. Research Plan

The remaining three studies are described here.

5.1 Study 2: Assessment of Existing Websites (in progress)

The aim of this study is to develop a primary and secondary categorized set of Websites about HRQOL and prostate cancer. These sets will then be used in subsequent studies, and the categorization method and results will serve as an independent contribution of this research program.

Methods

A list of 100 Websites about HRQOL issues in prostate cancer will be generated through a multi-pronged search strategy, including search engines, referrals from experts such as urologists and patient educators, referrals from trusted sites, referrals from men with prostate cancer, and lists from books and magazines.

Websites will be cached locally using open-source Web-mirroring software.¹ Caches will be dated. Caches will be used as references in case of changes in Website design, but in general, live sites will be used so as to not diminish the dynamic nature of blogs, news sites, sites with automatic feeds and database-driven sites that require specific user feedback to generate their content.

Five experts – three in human factors and usability and two in prostate cancer care and HRQOL – will be recruited through personal contacts. Each expert will be given a list of 10 Websites selected randomly from the group of 100, and will be guided through a process of identifying distinguishing content and presentation

¹ HTTrack (<http://www.httrack.com/>)

attributes of the Websites according to Repertory Grid Analysis techniques (Cooke 1994, Kelly 1955.)

All the attributes will then be pooled, and the resulting list will be reviewed with all experts. Each expert will then be asked to rate a random selection of 30 Websites from the same original sample of 100 Websites according to each attribute. Ratings will also be conducted by the researcher and any significant discrepancies between ratings will be examined between the researcher and expert to reach consensus.

Analysis

The goal of this analysis is to identify a subset of 30 Websites, referred to as our "primary set," that (1) are representative of the solution space of Websites available on the topic of HRQOL and prostate cancer and (2) will act as anchors on the site attributes deemed to be of greatest interest. For example, via Repertory Grid Analysis, we may identify 'amount of numeric information' and 'extension: .com, .org, .edu, other' as distinguishing attributes. Therefore, within the primary set, we might wish to include sites with "low", "medium" and "high" amounts of numeric information and sites with each of the extensions listed. Additionally, a further 70 sites will be identified as a "secondary set." The purpose of the secondary set is to provide further richness within the solution space of Websites for use in the next study.

In order to identify the primary set, since the Website attributes will presumably contain a mix of categorical and ordinal variables, I will analyze the attribute ratings via factor analysis and select 30 Websites such that the set includes at least 2 Websites that load highly – one positively and one negatively – on each factor.

5.2 Study 3: User Rating of Existing Websites (planned)

The aims of this study are: (1) To gather a set of user satisfaction ratings for the Websites identified in the previous study and individual characteristics and attributes of study participants to populate a matrix for a recommender system for Websites about HRQOL issues in prostate cancer. (2) To refine hypotheses concerning individual characteristics as predictors of preferences for content and presentation of Web-based information about HRQOL issues in prostate cancer.

Methods

40 participants will be recruited via letters sent to patients at Princess Margaret Hospital's Prostate Centre and participants of Man To Man, a support group. Letters will be followed up with phone calls to ascertain willingness to participate and to screen for inclusion criteria. In order to be eligible to participate in the study, participants must have been diagnosed with prostate cancer, must speak English sufficiently well to hold a conversation over the phone, must have used the Internet within the past month, must have access to a private

email account and the Web or be willing to travel to downtown Toronto to use a Web-connected computer provided by the researchers, must be willing and able to provide the study researchers with clinical information such as their PSA at diagnosis, their last PSA, their Gleason score, their TMN stage currently and at diagnosis (if known.) Participants will be recruited to represent a range of experiences with prostate cancer treatments, education levels, as well as different stages of the disease and different time points in the cancer experience.

A subsample of participants (4-6 participants) must be willing and able to travel to downtown Toronto to participate in usability testing prior to beginning the full experiment. The invitation to participate in usability testing will be offered to all men who live in the Toronto area and participants will be accrued to the subsample on a first-come, first-recruited basis in order to incorporate their feedback about usability into a user-driven, iterative design approach.

Participants will be provided with an individual login and password to access a study Website, where they will be asked to complete a set of iterative online questionnaires at their own pace. The first set of questionnaires will be comprised of instruments intended to assess their individual characteristics such as demographic data (including Internet connection speed), clinical characteristics, current HRQOL, behavioural style, Health Locus of Control, literacy and numeracy, baseline self-efficacy for symptom control, anxiety, depression and social support. (See Appendix C for a list of instruments.) Following completion of the initial questionnaires, participants will be provided with a Web page showing five hyperlinks selected at random from the set of 30 primary Websites identified in the previous study. Clicking on a link will launch the site in a new browser window, and a record will be stored identifying the five sites in case a participant accidentally closes the window with the five links and wishes to return to where he left off.

The participant will be requested to view each site for as long or as short a time as he wishes and then to return to the study Website, where he will be asked to rate the site on a 5-point Likert scale and will have the option to provide additional free-form comments. Upon completing the ratings for all five sites, the participant will have the choice between clicking a button to obtain five new sites to rate, or choosing a number between one and fourteen from a drop-down list to complete in the phrase, "Email me in ___ days so I can see more Websites."

Participants who finish all 30 sites in the primary set will be informed that they have completed the primary portion of the experiment. They will be thanked for their contribution and offered the opportunity to continue rating sites. For men who choose to view more Websites, further sites will be again selected randomly in groups of five, this time from the secondary set of 70 sites.

Technical statistics such as browser, screen resolution, and time between clicking a hyperlink and recording a rating, as well as study statistics such as number of sites rated and drop-out rate will be recorded.

Upon completion of the experiment, participants will be contacted via email and requested to complete

an online exit interview involving measurements of self-efficacy for symptom control, anxiety, depression, social support and open-ended questions about their feelings about the information available online to do with HRQOL and prostate cancer.

Analysis

The goal of our analysis is to determine first, whether certain user characteristics predict preference for certain sites and second, if yes, what distinguishes those sites from others? This will be accomplished via forward stepwise discriminant analysis with variables hypothesized to be of greatest interest (HRQOL symptoms, behavioural style and literacy/numeracy scores) added to the model first. Groups of sites will be compared according to their attributes as identified in the previous study via MANOVA.

Secondary analyses will be conducted to address questions such as: Are there individual characteristics that predict whether a participant chooses to continue rating sites after the initial set of 30? (Assessed via ANOVA.) Is there a difference in self-efficacy scores before and after the experiment? (Assessed via paired t-test.)

5.3 Study 4: Evaluation of Prototype Websites (planned)

The primary objective of this study is to evaluate, via user satisfaction ratings over the course of a longitudinal experiment, two tailored Website prototypes for men with prostate cancer. Site A will be designed to implement a prototype recommender system for Websites about HRQOL and prostate cancer. Site B will be designed to communicate HRQOL scores via different presentation methods to men who wish to see them.

Secondary objectives of this study include evaluating the effects of providing tailored Web-based information about HRQOL and prostate cancer on men's self-efficacy for symptom control, anxiety, depression, social support and HRQOL scores.

Methods

100 participants will be recruited via a variety of methods:

Men who participated in Study 3 will be invited to participate in Study 4 as well. It is expected that between 10 and 20 of the 40 men from study 3 will agree to participate in study 4.

Additional participants will be recruited via letters sent to patients at Princess Margaret Hospital's Prostate Centre and participants of Man To Man, a support group. Letters will be followed up with phone calls to ascertain willingness to participate and to screen for inclusion criteria.

Further participants will be recruited online via posts on Internet forums to do with prostate cancer, contact with bloggers with prostate cancer, and online contact with researchers in other locations.

Inclusion criteria are identical to those of study 3. Also, as in study 3, a subsample of local participants (4-6 participants) will be recruited to participate in usability testing as part of the iterative design process prior to beginning the full experiment.

Participants will be provided with an individual login and password to access a study Website, where they will be asked to complete a set of iterative online questionnaires at their own pace. The first set of questionnaires will be comprised of instruments intended to assess their individual characteristics such as demographic data (including Internet connection speed), clinical characteristics, behavioural style, Health Locus of Control, literacy and numeracy, baseline self-efficacy for symptom control, anxiety, depression, social support and current HRQOL. (See Appendix C for a list of instruments.)

Following completion of the initial questionnaires, participants will be provided with a Web page of instructions showing two hyperlinks: one to Site A, a prototype recommender system for Websites about HRQOL and prostate cancer, and one to Site B, a prototype display of the participant's individual HRQOL score. Participants will be requested to view Site A; viewing Site B will be presented as an optional activity.

Upon first clicking the link to Site A, participants will be assigned randomly to one of four study arms:

- (1) Control. The control group will see the list of 30 Websites from Studies 2 and 3, ranked according to pooled preference ratings obtained in Study 3.
- (2) Collaborative filtering (CF). The CF group will see the list of 30 Websites from Studies 2 and 3, initially ranked according to pooled preference ratings obtained in Study 3.
- (3) Content-based filtering (CBF). The CBF group will see the list of 30 Websites from Studies 2 and 3, organized and ranked according to Website attributes from Study 2 and the relationships derived in Study 3 between the attributes and individual factors of participants.
- (4) Hybrid filtering (HF). The HF group will see the list of 30 Websites from Studies 2 and 3, initially organized and ranked according to Website attributes from Study 2 and the relationships derived in Study 3 between the attributes and individual factors of participants.

In all four conditions, rankings of sites will change dynamically accordingly to the rules of the appropriate system over the course of the experiment. Participants in all of the arms will be able to rate all Websites, write brief reviews and submit new Websites. Additions of such Websites to the set of existing sites within the systems will proceed as per the rules for that system.

Upon first clicking the link to Site B, participants will be presented with four options for viewing their HRQOL score: text without numbers, text with numbers, graph without numbers, and graph with numbers. All four options will be shown concurrently on the screen in a 2x2 grid. The order of arrangement of the four options will be random. When the participant clicks on any one of the options, it will automatically enlarge to fill the window. The participant will be asked to rate each display option and to choose one display that will be

saved as his preferred format. He may choose any one of the four formats or the initial 2x2 grid as his preferred display. His subsequent viewings of Site B throughout the experiment will automatically default to his preferred display. The other formats will remain accessible and he may change his preferred display at any time.

The experiment will run for four months, with email reminders sent once each month to remind participants to view the prototype Websites and submit their ratings and/or other recommended sites to the system. The emails will be sent to all participants who have not formally withdrawn from the experiment, regardless of participation patterns.

Technical statistics such as browser, screen resolution, and time between clicking a hyperlink and recording a rating, as well as study statistics such as number of sites rated, number of new sites submitted, number of logins, time spent on the site and drop-out rate will be recorded.

Upon completion of the experiment, participants will be contacted via email and requested to complete an online exit interview involving measurements of general satisfaction with the prototype Website, self-efficacy for symptom control, anxiety, depression, social support and open-ended questions about their feelings about the information available online to do with HRQOL and prostate cancer.

Analysis

The primary goal of this analysis is to determine whether the different recommender systems garner different satisfaction ratings overall and/or for particular types of users. This will be tested via factorial ANOVA on satisfaction ratings and the individual variables predicted to be of greatest influence on individual needs: HRQOL symptoms, behavioural style (monitoring/blunting) and education factors such as health literacy and numeracy.

Further analyses will examine questions such as whether different recommender systems have different drop-out rates (tested via one-way ANOVA) and whether provision of tailored information about HRQOL and prostate cancer influences self-efficacy for symptom control (tested via ANCOVA with baseline self-efficacy as the covariate.)

I will also examine individual preferences for feedback about HRQOL scores, namely whether men who are symptomatic and/or who score highly as monitors are more likely to wish to receive the information and whether numeracy scores affect the preferred display format. These questions will be tested via MANOVA.

6. Contributions and Relevance

The proposed research program, upon completion, will contribute the following:

1. Identify the key factors within individuals that determine their needs concerning information content and

presentation strategy relating to prostate cancer HRQOL.

2. Develop a method for classifying prostate cancer websites in terms of information types and presentation strategies.
3. Develop a method for matching types of individual to types of website.
4. Develop a recommender system for recommending websites to people based on the scores that they have on the key factors.
5. Present experimental results demonstrating the benefits of appropriate filtering on one or more key outcomes.
6. Present experimental results demonstrating the individual differences that predict preferences for viewing or not viewing HRQOL feedback.

7. Progress and Timetable

Table 3. Timetable of research program milestones.

Task	Timeline
Course work	completed
Literature Review	ongoing
Study 1: Interviews	completed
Qualifying Exam	completed
Thesis Seminar	April 2007
MS Study 1 (Target Journal: Health and Quality of Life Outcomes)	July 2007
Study 2: Assessment of Existing Websites (in progress)	Mar 2007 – Jul 2007
MS Study 2 (Target Journal: Human-Computer Interaction)	September 2007
Thesis Progress Meeting	October 2007
Study 3: User Rating of Existing Websites (planned)	Sep 2007 – Dec 2007
MS Study 3 (Target Journal: JMIR)	Feb 2008
Study 4: Evaluation of Prototype Websites (planned)	Jan 2008 – May 2008
MS Study 4 (Target Journal: JAMIA)	June 2008
Thesis Writing	Jul 2008 – Dec 2008
Final Exam	Jan/Feb 2009

Appendix A: References

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Appendix B: Glossary of medical terms

Comorbidity: “[T]he presence of coexisting or additional diseases with respect to an initial diagnosis or with respect to the index condition that is the subject of study, Comorbidity may affect the ability of affected individuals to function and also their survival; it may be used as a prognostic indicator for length of hospital stay, cost factors, and outcome or survival.” (<http://cancerweb.ncl.ac.uk>, accessed September 14, 2005)

Gleason score: A numerical assessment by the pathologist examining a prostate biopsy indicating the aggressiveness of a cancer. Scores of 1 (less aggressive) to 5 (most aggressive) are assigned to the two largest areas of cancer activity in a biopsy tissue sample, creating an integer Gleason score on a scale of 2 to 10. (Canadian Prostate Cancer Research Initiative - Large Centre Training Grant classes, Princess Margaret Hospital, January – April 2004.) Gleason scores of 2-5 indicate very benign cancers; scores of 6-7 often indicate a need for surgery or radiation; scores of 8-10 indicate aggressive cancers that require surgery, radiation or hormone therapy. (Jamnicky & Nam 2003)

PSA: Prostate Specific Antigen. “A protein produced by the prostate gland; high [or rising] PSA levels could indicate the presence of prostate cancer.” (Jamnicky & Nam 2003)

TMN stage/Cancer stage: An indication of how far the cancer has progressed:

Table 4: TMN Staging System

<i>Stage</i>	<i>Description</i>
T1	The tumor cannot be felt or seen using ultrasound.
T1a	Cancer cells are incidentally found in 5 percent or less of tissue samples from prostate surgery for benign disease.
T1b	Cancer cells are found in more than 5 percent of surgery-sample tissue.
T1c	Cancer cells are identified by needle biopsy because of high PSA.
T2	The cancer is confined to the prostate, but can be felt as a small, well-defined nodule.
T2a	Tumors are in half a prostate lobe.
T2b	Tumors are in more than half a prostate lobe.
T2c	Tumors are in both lobes.
T3	Tumor extends through the prostate capsule.
T4	Tumor is fixed to or invades adjacent structures.
N0	Regional lymph nodes are still cancer-free.
N1	A small tumor is in a single pelvic lymph node.
N2	A medium-sized tumor is in one lymph node, or small tumors are in several nodes.
N3	A large tumor is in one or more lymph nodes.
M0	Cancer has not spread beyond the regional lymph nodes.
M1a	Cancer has spread to lymph nodes distant from the regional nodes.
M1b	Cancer has invaded the bones.
M1c	Cancer has spread to other sites.

(Jamnicky & Nam 2003)

Appendix C: Survey Instruments

Current HRQOL

HRQOL will be assessed via the PORPUS. As described in section 3.1, the PORPUS has been shown to be reliable, valid and sensitive in prostate cancer patients (Krahn et. al. 2000, 2003, 2005).

Comorbidity

Comorbidity will be assessed via medication count. Users will be asked to count how many prescription medications they take regularly aside from any that have to do with prostate cancer, its HRQOL effects or side effects of prostate cancer treatments. Medication count has been shown to be an effective proxy for longer, more time-consuming measures of comorbidity (Clark et. al. 1995).

Treatment(s) Received

Treatment(s) received will be assessed by presenting users with a list of treatments for prostate cancer and asking them to check which treatment(s) they have received. An option will be provided to “write-in” treatment(s) that are not on the list and layperson definitions of each treatment will be provided. Participants will be instructed that if they tried a treatment briefly but decided not to continue with the treatment, that they should note that in the comments section of the form. For example, if a man tried hormone therapy but stopped after his first injection because he didn’t like the side effects, then he may check ‘yes’ to the question, ‘Have you had hormone injections?’ but should note that distinction on the form. Participants will also be asked to specify the approximate start and end dates of each treatment they have received.

Cancer Stage(s) as a Function of Time

Participants will be asked to indicate the TMN stage of their prostate cancer at diagnosis, and at any points of change in their prostate cancer experience. If this is not known, it will be sufficient for the participant to indicate whether or not there is evidence that his cancer has spread to his bones or other organs, and if so, when this was determined.

PSA as a Function of Time

Participants will be asked to indicate, at minimum, their last PSA. If possible, they will also be asked to provide the dates and results of any previous PSA tests they can recall or for which they have records, including their PSA at diagnosis.

Gleason score

Participants will be asked to indicate their Gleason score at diagnosis.

Year of Diagnosis

Participants will be asked to indicate the year in which they were diagnosed with prostate cancer.

Communication Preferences

Participants' communication preferences will be assessed with the Communication Preferences Inventory (CPI) (Parker, Chignell, and Ruppenthal, 2002). If it proves suitable to do so, the scale will be restricted to applicable subscales only, for example the subscale that addresses respondents' work-related communication availability may be adapted or removed to reflect the high percentage of prostate cancer patients who are retired.

Stage of Change

Stage of change will be assessed for behaviour changes relating to symptom control. The stages will be identified by asking the participant whether he intends to make any changes to his behavior, whether he intends to change behaviour within the next 6 months or 30 days, or whether he has already made such a change within the past 6 months or greater than 6 months ago (Prochaska et. al. 1997).

Behavioural/Coping Style

Coping style will be assessed with the Miller Behavioral Style Scale (MBSS) (Miller 1995). This scale asks people to imagine their responses to hypothetical threat scenarios and indicate with whether or not they would be likely to take certain actions to cope with the threat. The MBSS produces scores on two subscales: the *monitoring* subscale and the *blunting* subscale. Respondents may score high or low on either scale, creating four possible classifications. People with high monitoring and low blunting scores will be classified as *monitors*. People with low monitoring and high blunting scores will be classified as *blunters*. People may also have high or low scores on both subscales, though this is uncommon. Such people will be classified into two groups of *mixed monitors/blunters*.

Health Locus of Control

Health Locus of Control will be assessed via the Multidimensional Health Locus of Control Scales (Wallston et. al. 1978). These scales show good internal consistency ($\alpha = .673$ to $.767$ for short forms, $.830$ to $.859$ for long forms.) Validity and sensitivity have been demonstrated across a variety of populations.

Literacy, Health Literacy, Numeracy, Health Numeracy

Two common health literacy assessments used in general populations, the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA) will be considered for use. Further study is required to identify the most appropriate test of Health Literacy and Health Numeracy in this population.

User Satisfaction

User satisfaction will be assessed via one or more Likert scales. Potential questions include, “How useful did you find this Website?” and, “How satisfied do you feel about your experiences on this Website?”

Self-Efficacy for Symptom Control

Self-efficacy for symptom control will be assessed in two ways. The first instrument will be a visual analog scale. For example, the question may be posed, “How confident do you feel that you can manage your prostate cancer-related symptoms such as pain, incontinence, sexual dysfunction, etc.?” and the participant will be asked to indicate his confidence on a scale of 1 to 10.

The second instrument will be the *Self-Efficacy for Symptom Control* Inventory (Campbell et. al. 2004). This instrument, along with a companion scale for partners of men with prostate cancer, was developed for use in prostate cancer patients and was adapted from a measure of self-efficacy for pain management. The scale contains three subscales named Symptom Management, Physical Function and Coping. The overall scale and subscales all show good internal consistency, with Cronbach’s alpha coefficients of 0.97 for the total and 0.94 for each subscale (n=45). While the published literature on this scale does not show any explicit tests of convergent validity, the scale and subscales have moderate (0.44 – 0.71) Pearson correlations with most of the relevant HRQOL domains, giving some evidence of validity.

Anxiety & Depression

Anxiety & Depression will be assessed via the Hospital Anxiety & Depression Scale. This scale has been used widely for over 20 years and reliability, validity and responsiveness have been demonstrated across various populations (Herrmann 1997).

Social Support

Social Support will be assessed with the Medical Outcomes Study Social Support Survey (MOSSSS) (McDowell & Newell 1996). This scale was developed for patients with chronic diseases. Items assess whether

the respondent has a particular form of social support none of the time, a little of the time, some of the time, most of the time, or all of the time. This scale consists of four subscales:

<i>Subscale</i>	<i>Sample Item</i>
Tangible support	Someone to take you to the doctor if you needed it
Affectionate support	Someone to give you hugs
Positive social interaction	Someone to get together with for relaxation
Emotional or informational support	Someone to confide in or talk to about yourself or your personal problems

This scale has high internal consistency. Cronbach's alpha for the scale as a whole is 0.97; subscales have values between 0.91 and 0.96. McDowell & Newell (1996) state, "The preliminary evidence for reliability and criterion validity are impressive. The criterion validity coefficients are logical, and higher than those for other scales."

Appendix D: Usability Issues

Usability issues that have been identified in usability testing are listed below. These issues will be addressed in the next version of the site.

- Vertical scrolling on page 1 of the PORPUS Survey is not obvious.
- Users are unsure of how to enter responses in combo boxes.
- Some users do not know:
 - The treatments they have received.
 - What certain treatments are.
 - Their date of diagnosis.
- Large targets occasionally result in accidentally selecting an unintended response option.
- Many users dislike the categories in ‘marital status’ and suggest that ‘married’ and ‘common law’ should not be grouped together.
- Some users are uncertain as to how many answers are allowed on PORPUS questions.
- Some users were unsure of how to answer Porpus questions:
 - Sexual Function and Sexual Drive: Users were not sure how to separate these concepts.
 - Urinary Frequency and Urgency and Leaking Urine: Users were not sure how to separate these concepts.
 - Pain and Energy: Users were unsure whether they were supposed to answer only as their pain related to prostate cancer or whether knee pain, for example, counted.
- Many users expressed additional, clarifying information for their answers.

Appendix E: Patient Interviews – Interview Protocol

The interview protocol is reproduced here with blank space for note-taking removed.

1. Introduction & Consent Form [2 minutes]
2. Questionnaire A and CBI-B [5 minutes]
3. Porpus Prototype [10 minutes]

Comments:

4. *Having just completed the online questionnaire, what would you want to see here? What kind of information would you find most interesting and/or useful?* [2 minutes]

Comments:

5. Show results pages in random order. Ask for ranking from favourite to least favourite. [3 minutes]
general _____
result + distrib _____
result + advice _____
result + distrib + advice _____
+/- _____

Comments:

6. *Which do you prefer? Why? What do you like or dislike about the different results formats? Do you think it is a negative or positive thing to know whether one is above or below average?* [2 minutes]

Comments:

7. Questionnaire B. [3 minutes]
8. Questionnaire C and CBI-B. [3 minutes]
9. *Do you seek out information about prostate cancer outside of doctor's visits or do you prefer to not think about your prostate cancer unless you have to?* [1 min]

Comments:

- a. *If yes, what kind of information do you look for?*
 - b. *Do you look on the Web? Why or why not?*
10. *Do you talk about your prostate cancer with any other people? If yes, who? (family, other patients, etc.)* [1 min]

Comments:

11. *Are you interested in talking about your experiences with prostate cancer with other men who have prostate cancer?* [1 min]

Comments:

- c. *If yes, would you do that online or would you only do it in person?*
12. Any other comments?
 13. Thank you.

Appendix F: More Results of Patient Interviews

Means comparisons of responses to Questionnaire A before and after interacting with the prototype Website are shown here. Analyses were conducted via paired t-tests.

Paired Samples Test: Responses Before and After Interacting with Prototype Website

		Paired Differences					t	df	Sig. (2-tailed)
		Mean	Std. Dev.	Std. Error Mean	95% Confidence Interval of the Difference				
					Lower	Upper			
Pair 1	I feel hopeful and optimistic about my Quality of Life.	.04	.599	.117	-.20	.28	.328	25	.746
Pair 2	I do not need to seek additional information about how prostate cancer and it(s) treatments may affect my Quality of Life because my doctor will tell me everything I need to know.	.84	1.573	.315	.19	1.49	2.671	24	.013
Pair 3	I think that my Quality of Life is normal considering the disease(s) I have and the treatment(s) I have received.	-.12	.711	.140	-.40	.17	-.827	25	.416
Pair 4	I am interested in communicating with other men who have prostate cancer about out experiences with this condition.	.54	1.351	.276	-.03	1.11	1.965	23	.062
Pair 5	I feel very alone in my experiences with prostate cancer.	.27	1.589	.312	-.37	.91	.864	25	.396
Pair 6	When it comes to my health, whether the news is good or bad, I want to know.	-.08	1.294	.254	-.60	.45	-.303	25	.764

Descriptive statistics of responses to Questionnaire B are shown here:

Descriptive Statistics: Responses After Interacting with Prototype Website

	N	Minimum	Maximum	Mean		Std.
	Statistic	Statistic	Statistic	Statistic	Std. Error	Statistic
QB1: The PORPUS Website was easy to use.	27	1	7	6.07	.30	1.567
QB2: I would visit a Website like this on my own.	28	1	7	5.25	.35	1.858
QB3: I would discuss my results with my doctor.	28	5	7	6.14	.13	.705
QB4: If the Website showed me that my results were above average, I would feel better for knowing that.	28	4	7	6.11	.16	.832
QB5: If the Website showed me that my results were below average, I would feel worse for knowing that.	28	2	7	5.21	.28	1.475
QB6: I would want to see my results, even if they were below average.	28	5	7	6.50	.12	.638
Valid N (listwise)	27					

Bar plots of results page ranks are shown here. Four different prototype results pages were shown to each participant and he was asked to rank them in order of preference, with 1 being his first choice and 4 his last.

