

e-Health and Prostate Cancer Screening

An Assessment of the Quantity and Quality of Online Information

Prepared for
Andrology Australia

By
Dragan Ilic, Sally Green
Monash Institute of Health Services Research

2005

This literature review was written and prepared by the Monash Institute of Health Services Research and undertaken as part of the objectives of Andrology Australia (Australian Centre of Excellence in Male Reproductive Health).

Monash Institute of Health Services Research acknowledges Andrology Australia as initiated by the Australian Government Department of Health and Ageing for its financial support and commitment towards this Project.

Suggested citation:

Ilic D (2005): *eHealth and Prostate Cancer Screening. An Assessment of the Quality and Quantity of Online Information*. Andrology Australia. Education Report, Issue 3.

Chief Investigator: Dr. Dragan Ilic
Monash Institute of Health Services Research

Any enquiries or comments in regard to this publication should be directed to:

Dragan Ilic, PhD
Research Fellow
Monash Institute of Health Services Research,
Clayton Victoria 3168
AUSTRALIA

Telephone: + 61 3 9594 7523
Fax:
Email: dragan.ilic@med.monash.edu.au

© Andrology Australia 2005

No part of this publication may be reproduced by any process without written permission from Andrology Australia, apart from any use as permitted under the Copyright Act 1968. Requests for permission to reproduce this publication should be directed to the CEO, Andrology Australia, c/o Monash Institute of Medical Research, Monash Medical Centre, 246 Clayton Road, Clayton, Vic 3168.

Contents

Executive Summary	1
Introduction	9
1.1 Prostate Cancer Screening and the Internet.....	9
1.2 Men’s Health Attitudes and Information Needs	12
1.3 Patient Education	14
1.4 Healthcare and the Internet	15
1.5 Aims	18
Methods.....	19
<i>Part I – The Consumer Perspective on PCS</i>	19
2.1 Research Design.....	19
2.2 Recruitment.....	19
2.3 Focus Group Structure	20
2.4 Data Analysis	21
<i>Part II – The Nature and Quality of Online Information Regarding PCS</i>	21
2.5 Search Strategy	21
2.6 Website Relevancy and Exclusion Criteria.....	23
2.7 Assessment of Search Engine Efficiency and Quality of Information.....	24
2.8 Data Analysis	26
Results	27
<i>Part I – The Consumer Perspective on PCS</i>	27
3.1 Screening for Prostate Cancer	28
3.2 Knowledge	29
3.3 Access to Information	30
3.4 Duty of Care.....	31
<i>Part II – The Nature and Quality of Online Information Regarding PCS</i>	34
3.7 Search Engine Efficiency.....	34
3.8 Search Strategy	36
3.9 Quality of Online Information	37
3.10 Website Characteristics.....	41
3.11 Commissioning Agencies.....	43
3.12 External Agency Approval.....	45
3.13 The Role of Domains	47
3.14 Comparison of Online Information to the Available Evidence.....	49
4.1 Overall Findings.....	61
Conclusions and Recommendations.....	73
5.1 Conclusions.....	73
5.2 Recommendations.....	74
Appendices	79
Appendix A: Focus Group Information Sheet	79
Appendix B: Focus Group Consent Forms	83
Appendix C: DISCERN Tool.....	84
Appendix D: Levels of Evidence	85
Appendix E: Audited Financial Statement.....	86

Executive Summary

Introduction

Prostate cancer is a leading cause of cancer death in men worldwide. Screening for prostate cancer aims to decrease mortality and morbidity from the disease by increasing the chances of successful treatment through early detection. Currently there is a lack of evidence to establish if screening achieves this aim. This is illustrated by the conflicting recommendations offered by medical organisations.

In the absence of evidence patients must rely on their own beliefs and guidance from doctors to make an informed decision. Patients have traditionally adopted a passive role when discussing medical issues and decisions with their doctor. However, if a patient must live with the consequences of a medical decision, then the opportunity to accept or reject the decision must be made available to the patient. This has encouraged patients and doctors to adopt a shared approach to healthcare.

Doctors have traditionally informed patients about medical issues. These days more patients wish to take an active role in the decisions that may affect their health outcomes. This has been achieved through the use of patient education materials, such as written pamphlets and videos.

Male sexuality is networked by a complex interaction of personal, social and cultural factors. Any possible threat to the reproductive organs may negatively affect a man's gender perceptions. These masculine psychosocial factors have been identified as a

barrier in the attempt to promote men's reproductive health. Previous studies have identified men's reluctance to access information or health services in a bid to stave off this perceived threat to their masculinity.

Men treated for prostate cancer have reported difficulty in accessing relevant health information unless they were already in the healthcare system, i.e. consulting with a doctor. The Internet has been touted as an alternative resource where men can anonymously access health information tailored to suit their information needs.

The inception of the Internet, and its subsequent growth, has seen it develop as a communications network applicable in the healthcare context. Unlike traditional patient education materials, the Internet has the potential to offer a more tailored approach to patient education that may better compliment patient knowledge and information requirements.

Search engines have been developed in an attempt to aid the search for online information. General search engines provide a broad index of websites while meta-search engines attempt to provide a more precise index. Similarly medical search engines have been developed in an attempt to index websites that only offer medical information.

Despite the potential benefits of the Internet as a health education tool, uncertainty remains with respect to the suitability of the Internet as a health resource. This uncertainty has stemmed from the diverse nature of online information and the lack of editorial control and governance. Patients accessing poor quality information from the

Internet risk becoming misinformed. This has the potential to negatively impact on their health outcome.

Study Aims

The aims of this study were to identify;

- i) What are the information needs and attitudes of potential consumers with respect to PCS?
- ii) How much information about PCS is available on the Internet and what is the most effective way of finding it?
- iii) How valid and relevant are existing websites in providing information about PCS?

Study Design

A qualitative study design using focus groups was conducted with a total of 67 men to identify men's attitudes and information needs on PCS. Purposeful and snow ball sampling techniques were used to recruit men diagnosed with prostate cancer (PC) and asymptomatic men (NPC). Standard questions were developed from a review of the literature, with the resultant semi-structured interview questions facilitated by the same male facilitator. Focus groups were audiotaped and transcribed verbatim, allowing the extraction of key themes using an iterative approach.

Eleven keyword searches were performed on 15 search engines, representing general, medical and meta-search engines to assess the quality of online information. The first 50

websites returned from each search were analysed for quality of information using the DISCERN rating tool. The quality of website information was also assessed by extracting the presence or absence of website characteristics that may be indicative of a higher quality of information. In addition to descriptive analysis, search engine efficiency and the quality of website information was analysed by performing two-tailed Mann-Whitney U-tests and one-way Kruskal Wallis ANOVAs.

Key Findings

Matching attitudes and information needs on PCS were expressed by asymptomatic men and those with a previous diagnosis of prostate cancer. Poor health knowledge, limited access to health information and a poor patient/doctor relationship contributed to a poor understanding of prostate cancer and its screening. The presence of psychosocial masculine attitudes also exacerbated these attitudes. Despite the presence of these barriers all participants were in favour of screening for prostate cancer. The Internet was also identified as a potential source for accessing good quality health information on PCS.

From 6690 websites reviewed, 84 were identified as unique websites providing relevant information on PCS. A total of 68 unique websites were returned by general search engines, in comparison to 18 and 44 returned by medical and meta-search engines respectively. Both general and meta-search engines were significantly more effective at retrieving relevant information to PCS than were medical search engines. The quality of information relating to PCS was variable with 56% of websites providing information of a low standard, with the mean \pm SD DISCERN score for all websites being 2.51 ± 0.74 (1

= 'poor', 5 = 'good'). There was no difference in the quality of websites sourced by the different types of search engine. Websites that provided a link to other medical resources and a citation of evidence contained a higher quality of information. Conversely websites that provided a direct service (eg. screening tests for prostate cancer) contained poorer quality information. The majority of websites (48%) provided a recommendation supporting PCS, of which 10% provided evidence to support this statement. Forty one per cent of websites discussed both the potential benefits and harms of PCS, with only 17% qualifying their position with evidence. The remaining 11% of websites provided a recommendation against PCS, a third of which provided evidence to support their stance.

Conclusions

This study identified that despite a lack of health knowledge and limited access to health information men were unanimously in favour of screening for prostate cancer. It was also identified that the Internet could potentially be a good source of health information for men. The overall quality of information about PCS on the Internet was of a variable quality. Both general and meta-search engines were identified as the most efficient way of sourcing websites with information related to PCS.

The existence of psychosocial masculine attitudes primarily negates the manner in which men interact with their doctor, utilise health services, access health information and contemplate their well being. The Internet provides men with a vehicle to access health information in an environment that circumvents the influence of these identified barriers. Utilising this technology may assist health professionals in the further promotion of

men's reproductive health issues. Greater consumer awareness is needed in order for the public to gain a true benefit by using the Internet as a health resource. Educating consumers with regard to quality issues about health information may increase their ability to source quality online information. This may be achieved by highlighting;

- Use of different types of search engines and their impact
- Influence of specific website characteristics on the quality of information
- Use of consumer rating tools such as DISCERN to reach an independent assessment of website quality
- Provision of guidelines/tools to doctors and health professionals that may assist patients' search for health information on the Internet

Recommendations for Future Research

- Identify how educating men about accessing and evaluating online health information affects their satisfaction with information sourced
- Identify how health information presented on the Internet affects patient knowledge and health outcomes in comparison to traditional sources of patient education such as video and written information

Project Summary

1. Selected research findings from this project have been submitted and published in the following journal as peer reviewed articles;

- Ilic D, Risbridger G, Green S. The informed male: attitudes and information needs on prostate cancer screening. *Journal of Men's Health and Gender* 2005; 2(4):414-420.
- Ilic D, Risbridger G, Green S. Searching the Internet for information on prostate cancer screening: An assessment of quality. *Urology* 2004; 64(1):112-116.

2. Selected research findings from this project have been presented at the following conferences;

- To Screen or Not to Screen: The Online Opinion on Prostate Cancer Screening. 12th Cochrane Colloquium, Ottawa, Canada, October 2004
- To Screen or Not to Screen: The Online Opinion on Prostate Cancer Screening. 3rd Annual World Congress on Men's Health, Vienna, Austria, October 2003

Introduction

1.1 Prostate Cancer Screening and the Internet

Prostate cancer is the second most common cause of cancer and the leading cause of male malignancy across the world.¹ Age and family history have been identified as risk factors associated with prostate cancer, with diet and ethnicity postulated as potential risk factors.²⁻⁸ Prostate cancer is diagnosed by performing a triad of tests including a digital rectal examination (DRE), a prostate specific antigen (PSA) test and a transrectal ultrasound (TRUS) guided biopsy. Advocates for prostate cancer screening (PCS) suggest that screening will decrease patient mortality and morbidity. However, the true benefit of PCS is currently unknown due to a lack of high quality evidence. This has caused widespread debate within the medical community as opponents argue that PCS may promote unwarranted procedures that may negatively impact upon the patient's well being. The various recommendations offered by recognised medical entities reflect the different positions associated with this debate, **Table 1.1**.

Table 1.1. Prostate Cancer Screening Recommendations (Adapted from the following references⁹⁻¹⁸)

Organisation	Recommendation
American Cancer Society	The American Cancer Society recommends that the PSA and DRE should be offered annually beginning at age 50 to men who have a life expectancy of at least 10 years. Men at high risk, including men of African descent (specifically sub-Saharan African descent) and men with a first-degree relative diagnosed at a younger age should begin testing at age 45.
American Urological Association	Early detection of prostate cancer should be offered to asymptomatic men 50 years of age or older with an estimated life expectancy of more than 10 years. It is reasonable to offer testing at an earlier age to men with defined risk factors, including men with a first-degree relative who has prostate cancer and African-American men.
American College of Preventive Medicine	The American College of Preventive Medicine recommends against routine population screening with DRE and PSA. Men age 50 or older with a life expectancy of greater than 10 years should be given information about the potential benefits and harms of screening and the limits of current evidence and should be allowed to make their own choice about screening, in consultation with their physician, based on personal preferences.
American Medical Association	The launching of mass screening programs for the early detection of prostate cancer is premature at this time. Prostate cancer screening, if elected by the informed patient, should include both prostate-specific antigen testing and digital rectal examination. Men most likely to benefit from tests for early detection of prostate cancer should have a life expectancy of at least 10 years and include: (a) Men 40 years of age or older of African American descent; (b) Men 40 years of age or older with an affected first-degree relative; and (c) Men 50 years of age or older.
Urological Society of Australasia	Population screening of asymptomatic men is not recommended. Individual men in the age group 50-70 with at least a 10 year life expectancy (or men >40 with a strong family history) should be able to undertake screening by annual DRE and PSA testing, after appropriate counselling regarding the potential risks and benefits of investigations, and the controversies of treatment.
US Preventive Services Task Force	The US Preventive Services Task Force concludes that the evidence is insufficient to recommend for or against routine screening for prostate cancer using prostate specific antigen testing or digital rectal examination.
NHS Centre for Reviews and Dissemination	Routine testing of men to detect prostate cancer should be discouraged, irrespective of family history.
The Swedish Council on Technology Assessment in Health Care	Routine population screening for prostate cancer is not recommended because of the lack of evidence regarding the benefits and the considerable risks of adverse effects.

American College of Physicians	Rather than screening all men for prostate cancer as a matter of routine, physicians should describe the potential benefits and known harms of screening, diagnosis and treatment; listen to the patient's concerns; and then individualise the decision to screen.
Canadian Urological Association	Men should be made aware of the potential benefits and risks of early detection so that they can make an informed decision as to whether to have this test performed.
British Association of Urological Surgeons Working Party	The Working Party feels that currently British urologists cannot take a definite view on this issue.

Despite the controversy regarding PCS, the 1990s saw an initial increase in the use of the PSA test followed by a decline as the decade drew to a close. This period also saw the initial explosion of the Internet, providing an ideal medium for men to search for information in a national and international forum to assist in formulating a decision. The availability of searching in an anonymous network may be important to men who may perceive such issues as embarrassing or emasculating.¹⁹⁻²² The Internet offers a medium in which the patient may formulate their own opinion in a bid to ease any concerns regarding this issue.

1.2 Men's Health Attitudes and Information Needs

Male sexuality is linked by a complex interaction between personal, social and cultural factors.²³ The potential diagnosis of prostate cancer may be perceived as a direct threat to the area intimately associated with sexual function. Such a threat can adversely affect a man's gender perceptions and health attitudes, particularly involving those of a reproductive nature.

A main barrier identified by men preventing them from seeking medical advice is a threat to their masculinity.^{24 25} Seeking medical aid for issues of a reproductive nature has been described as a sign of weakness by men, implying a lack of control over one's body.²⁴ This is manifested psychologically as an innate threat to their survival and a blow to their self image and ego.²⁵ Similarly, men may be reluctant to discuss or act upon issues related to reproductive health due to a level of embarrassment.²⁶⁻²⁸ The digital rectal examination is an example of a procedure that often enhances men's levels of embarrassment by feeding into these masculine attitudes.²⁹

Such attitudes may be bought about because many men are not well informed about the benefits, harms and implications of prostate cancer and its screening.^{26 30} This may lead to increased patient anxiety and confusion, ignorance of the health issue, or the implementation of self imposed barriers such as inconvenience or cost as defence mechanisms against seeking medical help.^{26 27 31} Fear of being diagnosed with prostate cancer may outweigh the potential value of any information, particularly if warned about a cancer that may potentially remain dormant.²⁶

Patients have traditionally sourced their health information from their doctor. The ability for patients to receive discernable materials on PCS that meet their information requirements may depend on their relationship with their doctor. The stronger the patient/doctor relationship is the more likely doctors are to engage in a discussion on the benefits and uncertainties associated with screening for prostate cancer.³² With increasing time constraints placed on health professionals, many patients feel the information offered by their doctor is rushed, inconsistent and sometimes too complex to comprehend.^{27 29 33}

1.3 Patient Education

Greater community accessibility to health information has seen a change in the patient-physician relationship. Patients have traditionally relied on their health professional to access health information through verbal and written practices. The Internet has given patients the power to directly access previously exclusive health information and in some instances avoid visiting their health professional to facilitate such requirements. This application of the Internet to medicine has given rise to the concept of e-health.³⁴ The emergence of e-health has contributed to the change from the patient seeking assistance from their health care provider to one where more emphasis is being placed on patient self-help and self-care.³⁵

What is e-health?

e-Health is the referral of health services or information through the use of emerging technologies, such as the Internet, in the fields of medicine, public health and business.

Traditional forms of patient education, such as books and pamphlets, tend to offer generic information. Individuals are increasingly turning to the Internet with the expectation that it may offer a more personalised source of information, one that complements their knowledge and information requirements.³⁶ Patients may now potentially acquire as much, or more information than their health professional by spending hours online in search for the most current and applicable health information.¹⁹ This knowledge allows patients the option to assume a greater responsibility for their health by actively participating in medical decisions. This has led to more patients taking a proactive rather than a reactive approach to their health.

1.4 Healthcare and the Internet

In 2002 approximately 580 million people world wide, and 10 million in Australia, had access to the Internet.^{37 38} It has been estimated that more than 85% of Internet users search the Internet for health related information, with between 25% and 55% of patients using the Internet to source specific medical information such as prostate cancer.³⁹⁻⁴³ Additionally an increasing number of health professionals also utilize the Internet as a health resource.^{43 44}

The Internet has the potential to answer any medical question through the facilitated access to medical information by the general public. Users have the ability to search through various levels of knowledge and evidence from a broad range of disciplines to identify information most relevant to them. Since the Internet is a dynamic medium it allows access to the most recent medical information often prior to its publication in text books or journals, due to the time delay associated with peer review.^{41 45} Similarly, retrieval of information is possible in the global sense and is not limited by international borders.

Although the Internet allows the rapid circulation of information to take place it also increases the potential for genuine medical resources to be represented along side those from a biased source or those seeking to make a profit from consumers.^{46 47} This makes it difficult for the consumer to distinguish between evidence based medical, anecdotal or fictional information.⁴⁸ Consumers are often unaware of the peer review process that traditional medical information undergoes prior to publishing in order to establish that the

information presented is valid.⁴⁹ The copyright, libel and privacy laws that exist in traditional media also apply to the Internet. However, as the Internet is an unregulated medium that operates across all geographical borders, it makes it extremely difficult to uphold any of these laws.

Search engines provide an index of the Internet, allowing an easy and efficient means of accessing and filtering through information, **Table 1.2.**⁵⁰⁻⁵⁴ Search engines can locate information, but they cannot provide an evaluation of the information they retrieve. Lack of quality standards can severely compromise the validity of information. Internet users predominately lack the medical knowledge necessary to accurately assess the quality and validity of online medical information.⁵⁵ Hence there is increased reliance on a variety of devices such as quality labels, consumer quality rating tools, gateway filtering pathways and third party recommendations to aid the user in forming an opinion on the quality of information, **Table 1.3.**

Table 1.2. Types of search engines available and their distinct features. (Adapted from the following reference³⁸)

Search Engine Type	Features
General	Provide a general form of structure and index of websites
Meta-Search	Provide a list of websites requested by the user by conducting simultaneous searches on various general search engines
Medical	Provide an index of websites that contain medical information

Table 1.3. Quality control methods available for online medical information. (Adapted from the following reference⁵⁶)

Tool	Example	Description
Quality label	Health on the Net (HON)	Websites marked with a quality label adhere to a defined list of quality criteria that promote good quality practice
Consumer Quality Rating Tool	DISCERN	A tool that allows the Internet user to appraise the quality of website information according to validated quality criteria
Gateway Filter	Organising Medical Networked Information (OMNI)	Index of medical websites selected by a third party according to a selection criteria
Third Party Recommendation	MedPICS Certification and Rating of Trustworthy Health Information on the Internet (MedCertain)	Appraisal of website information by medical experts

Previous studies have identified online information relating to reproductive topics to be of a variable quality, the majority of which is poor. No previous study has investigated the quality of information specifically relating to PCS.^{42 57 58} Despite the controversy surrounding the current evidence about prostate cancer, or lack of evidence with regard to recommendations on PCS, no study has been performed to evaluate the impact of this on the quality of information about prostate cancer on the Internet. As was the case with the women's health movement some 25 years ago, there is greater interest in issues of men's health. For the Internet to be an effective tool in men's reproductive health, education and health promotion about existing information on the Internet must be evaluated in order to identify the current information gaps.

1.5 Aims

The purpose of this study was to address the following research questions;

Part I – The Consumer Perspective on prostate cancer screening (PCS)

- What are the information needs and attitudes of men with respect to PCS?

Part II – The Nature and Quality of Online Information Regarding PCS

- How much information about PCS is available on the Internet and what is the most effective way of finding it?
- How valid and relevant are existing websites in providing information about PCS?

Methods

Part I – The Consumer Perspective on PCS

2.1 Research Design

The topic of prostate cancer screening and issues involving the male reproductive organs can be a sensitive issue for men to discuss. The use of focus groups is a suitable method to explore these issues as it allows the interaction between participants and the researcher in a group context, which may decrease their discomfort with the topic.⁵⁹ Additionally, focus groups provide a more naturalistic approach incorporating a range of communication processes exploring distinct participant attitudes, experiences and perspectives on the topic.^{59 60}

2.2 Recruitment

Participants were recruited through purposeful and snow ball sampling techniques in order to select information rich cases.⁶¹ Focus groups were conducted with men diagnosed with prostate cancer (PC) and asymptomatic men aged over 45 with no previous diagnosis of prostate cancer (NPC). This strategy was employed to compare and contrast findings between the two groups and identify how the diagnosis of prostate cancer impacts upon men's attitudes and information requirements toward PCS.

Participants for the PC focus group were recruited via advertisement from a database of participants who had previously been involved in focus groups and expressed an interest to be involved in future research. This database was made available by Andrology Australia who contacted participants on the researchers' behalf. Participants for the NPC

focus group were recruited through public advertisements placed in newspapers, private practice and distributed through Victorian Rotary groups. Focus groups were homogeneous with respect to education and residence (i.e. rural Victoria or metropolitan Melbourne).

Sampling also incorporated the recruitment of participants from a range of socio-economic and residential settings. Participants were required to provide written consent prior to their involvement with the study (Appendix A, B). Men who did not speak English or provide informed consent were excluded from the project. Ethical clearance for this study was received by the Monash University Standing Committee on Ethics in Research Involving Humans (SCERH).

2.3 Focus Group Structure

From March to November 2004 ten focus groups were conducted across metropolitan Melbourne and rural Victoria. Each group contained between six and eight men and lasted up to 1 ½ hours. Each focus group was homogenous with respect to diagnosis of prostate cancer, education and residence. Standard questions were developed from a review of the literature and asked in each of the focus groups by the same male facilitator. Each focus group was audio taped and transcribed verbatim. Focus groups were conducted until the data reached a point of ‘saturation’.

2.4 Data Analysis

Data was analysed by thematic analysis by extracting key themes and grouping the comments made under these themes.⁶² An iterative process was employed in re-grouping and identifying new themes as they emerged with the aid of the NVivo computer program.

Part II – The Nature and Quality of Online Information Regarding PCS

2.5 Search Strategy

A keyword search was performed on the Internet between April and May 2003 to identify websites providing relevant information on the topic of PCS. A total of 15 search engines were used, comprised of three different types – general, medical and meta-search engines, **Table 2.1**. The five search engines within each search engine category were chosen to represent those providing a large, medium and small index of websites. Search engines were chosen after examining the number of websites that are indexed by each search engine, as advised by each search engine website, and confirmed by cross-referencing these claims with online search engine publications. A total of eleven keywords were used across all search engines, **Table 2.2**. These were arbitrarily chosen to best represent the search strategies consumers may apply in their search for relevant online information.

Table 2.1. Websites used in the search strategy.

Search Engine	URL
General	
Alltheweb	www.alltheweb.com
AltaVista	www.altavista.com
Google	www.google.com
Teoma	www.teoma.com
Yahoo	www.yahoo.com
Meta-search	
Excite	www.excite.com
Ixquick	www.ixquick.com
Profusion	www.profusion.com
Surfwax	www.surfwax.com
Vivisimo	www.vivisimo.com
Medical	
HealthInsite	www.healthinsite.gov.au
MedlinePlus	www.medlineplus.gov
HON	www.hon.ch
NHS	www.nhsdirect.nhs.uk
Omni	www.omni.ac.uk

Table 2.2. Keywords used in the Search Strategy

'Digital Rectal Examination'	'DRE'
'Prostate Cancer'	'Prostate Cancer Diagnosis'
'Prostate Cancer Screening'	'Prostate Cancer Testing'
'Prostate Specific Antigen Testing'	'PSA Screening'
'PSA Testing'	TRUS Biopsy'
'Transrectal Ultrasound'	

None of the searches were restricted with regard to language, file format, domain, dates or listing/occurrence within a page. Non English language websites were included in order to realistically represent the types of websites that the consumer may be faced with when searching for online information. However, no websites in a language other than English were returned from the online searches. Upon running each search query examination of content was restricted to the first 50 listed websites, as most searches performed by individuals on the Internet rarely examine beyond the first 50 retrieved websites.⁵⁵

2.6 Website Relevancy and Exclusion Criteria

A website was categorized as relevant if it provided sufficient information to answer the question, 'What is prostate cancer and prostate cancer screening?' In particular, information was sought on the background of the condition, symptoms, diagnosis and screening regimes, and their implications. In addition to this primary criteria websites were excluded from analysis if they:

- Were repeated under a different URL (i.e. duplicated)
- Denied access to the website due to a 'dead' link, server unavailability or password requirements

- Acted as a portal, gateway or linked to information from another source
- Were discussion groups/chat forums.^a

2.7 Assessment of Search Engine Efficiency and Quality of Information

Search engine efficiency was measured as the percentage of relevant websites returned from the first 50 returned websites by each search query (i.e. number of relevant websites/total number of websites returned [e.g. 50]).⁵⁷ Quality of website information was assessed using the DISCERN tool (Appendix C).^{63 64} The DISCERN quality assessment tool was originally validated to assess written patient information about treatment options but has since been modified for use in validating health information on the Internet.^{63 64} The DISCERN quality assessment tool rates the quality of website information on a five point Likert scale (1 = ‘the publication is “poor” quality and has serious shortcomings and is not a useful or appropriate source of information about treatment choices’, 5 = ‘the publication is “good” quality and is a useful and appropriate source of information about treatment choices’). It has 16 key questions, each representing a quality criterion evaluating reliability, treatment choices and overall quality of the information.⁶⁵

^a Unlike information offered on websites, information provided in discussion groups/chat forums takes place in a dynamic medium, continuously throughout the day and night, i.e. ‘real time’. To evaluate the information offered by these forums a subjective period of selected time would need to be chosen to begin and cease the analysis of information. Such a process has the potential to bias the results. Conversely information presented on a website is static for the majority of its presentation, until any modifications are made. This provides an environment in which the information can be assessed at a given point in time.

In addition to the DISCERN tool, quality of website information was also assessed by extracting the presence or absence of website characteristics that may be indicative of a higher quality of information rating.⁵⁷ These characteristics are listed in **Table 2.3**. The quality of website information according to domain type (i.e. *.com*, *.org*, *.edu* etc.) was also noted. Finally, website information was assessed according to the extent to which the information was linked to and accurately reflected the available evidence, based on the National Health and Medical Research Council (NHMRC) recommended criteria for assessing dimensions of evidence (Appendix D).⁶⁶ Websites were categorised according to their recommendation (e.g. for/against screening) and then compared to the available evidence.

Table 2.3. Website Characteristics Investigated/Assessed

Is a target group identified?

Can a sponsoring agency be identified?

Is there a membership requirement/availability for users to access further information or services on the website?

Are any direct services available to users?

Do other websites link to the site?

Is there a statement regarding the currency of the information?

Are there any recognized statements regarding the updating of information?

Is the authorship of the website information recognized?

Are there referral links to other resources listed?

Is the website approved by an external source?

Is there any evidence cited for the website's information?

2.8 Data Analysis

The majority of data generated was descriptive and reported as such. Analysis of the correlation between the presence/absence of website characteristics and quality of information was performed using a two-tailed Mann-Whitney U-test. One-way Kruskal Wallis ANOVA's were performed to identify whether website quality scores differed across search engines, i.e. general, medical and meta-search, and across search strategies.

Results

Part I – The Consumer Perspective on PCS

A total of 67 men with a mean age of 64 ± 10.4 participated in the focus groups including 11 from a rural setting and eight from a non-English speaking background. Their demographic data are presented in **Table 3.1**.

Table 3.1. Demographic data of men participating in focus groups according to diagnosis of prostate cancer (PC) or no diagnosis of prostate cancer (NPC)

	PC (n=34)	NPC (n=33)
Age		
<i>Mean</i>	64.7 \pm 7.6	59.3 \pm 10.7
<i>45-55</i>	2	14
<i>56-65</i>	9	6
<i>65+</i>	23	13
Education		
<i>Primary</i>	4	1
<i>Secondary</i>	21	19
<i>Tertiary</i>	9	13
Marital Status		
<i>Married/partner</i>	25	31
<i>No partner</i>	9	2

The following themes on men's information needs and attitudes on PCS emerged from the focus group discussions.

3.1 Screening for Prostate Cancer

Men were unanimously in favour of screening for prostate cancer or at least being presented with an opportunity to be screened. Screening for prostate cancer was viewed as a preventive procedure that every man was entitled to receive. It was reasoned that early detection provided patients with the opportunity to treat the disease before it reached an untreatable stage.

"That [screening] is the one way to know to prevent it [prostate cancer], because they say that if you can discover it earlier you can cure it, but if it's too late then all you can say is goodbye." – NPC group

"I think you should go have the test, you may have it or you may have it at certain stages. But it can be monitored and you can have treatment, the operation or watchful waiting. It's not just saying that if you've got it [prostate cancer] you've got to have it [the prostate] out." – PC group

3.2 Knowledge

Participants in the NPC groups expressed a lack of knowledge and understanding of prostate cancer and issues associated with its screening. There was an understanding that men were susceptible to cancer of the prostate but few knew the function of the prostate, risk factors or what diagnostic procedures were available. Men in the PC group also supported these views, identifying they possessed little or no knowledge of prostate cancer before their diagnosis. A few men either had family members or friends that had been diagnosed with prostate cancer. Although this experience increased their awareness about the condition it did not necessarily increase their knowledge.

“My knowledge was limited to that of my father having contracted prostate cancer and subsequently dying of a result, but that was the extent of my knowledge.” – PC group

Community advertisements about prostate cancer and other men’s reproductive health issues were recognised as method to increase public awareness. Although such campaigns provided an initial peak interest in the issue, apathy toward the issue or the celebrity promoting the issue influenced participant’s decision not to act upon the message.

“You notice all these sportsmen with the roles get paid big money. Like the soccer star, what’s his name...Pele. That gets a bloke’s interest, but I don’t want to know about those [men].” – NPC group

Both groups drew parallels between screening for prostate cancer and screening issues in women’s health. Men were frustrated in attempting to comprehend why men’s issues, such as prostate cancer screening, had not achieved the same level of public appreciation as screening issues in women’s health. Men in the NPC group reasoned that women’s health had a greater awareness because women were willing to talk about issues relating

to their health whereas men are not. Men in the PC group hypothesised that political reasons were influencing the introduction of prostate cancer screening and if similar resources were invested in men's health as have been in women's health, the issue of prostate cancer screening would not be problematic. None of the men in the NPC group knew of the controversy surrounding prostate cancer screening, a view that was echoed by men in the PC group prior to their diagnosis.

"Women's health has been covered now to the point where breast cancer and cervical cancer awareness is an everyday thing, men, different situation." – NPC group

3.3 Access to Information

Both groups perceived a lack of information available on men's health and PCS. It was hypothesised that this deficiency impacted upon the limited knowledge men had about prostate cancer and their health in general. Men from the PC group also identified a lack of informed consent prior to their initial PSA test.

"We're all running an engine within ourselves but there's no bloody manual with it." – NPC group

The Internet was identified as a very useful resource of medical information. Participants were aware of major search engines but few believed they could use them effectively. Few had the confidence to assess the quality of website information and recognise quality information from anecdotal. Many men were concerned with the possibility of acting upon incorrect information obtained from the Internet and the negative effect it may present to their health. Men without access or limited experience using the Internet relied on Internet savvy family members and friends to conduct searches on their behalf and recommend websites.

“When you go to the ‘net generally to look, I mean there are just so many pages, and to decipher what’s what. I mean you’ve got to know the source, that’s the important thing. Where is all this stuff coming from?” – PC group

The ability to gather information from family members or friends who had either been tested or treated for prostate cancer was highly regarded, as their experiences were perceived to demystify the disease. Few men across both groups directly asked their general practitioner (GP) to provide information about screening for prostate cancer. Men in the PC groups identified support groups as a major resource for their information needs following their diagnosis, however neither group considered seeking information about prostate cancer screening from them. Participants were more likely to listen to the experiences of support group members when considering treatment options. It was acknowledged that men may find accessing information from support groups difficult due to the sensitive nature of the condition and perceived embarrassed associated with seeking information from strangers.

3.4 Duty of Care

Opinion was equally divided among both groups with respect to duty of care. Some men across both groups believed that men should take a greater interest and responsibility in broaching the subject of prostate cancer screening with their doctor. Proactively seeking screening was viewed as a preventive and accountable measure that should be initiated by the patient. The alternative viewpoint expressed by men in both groups was that the responsibility rests with the doctor to broach the subject and/or potentially incorporate it as part of an annual physical examination that men should maintain.

“Why can’t we take responsibility for our own actions?” – NPC group

“I get a reminder from my dentist to get my teeth checked every 12 months...I don’t recall them [doctors] saying ‘oh when was the last time you were checked for prostate cancer?’”

– NPC group

Participants believed that they had not formed any type of relationship with their GP.

This belief upheld by the perception that GPs cannot dedicate sufficient time to discuss issues pertinent to patients. Subsequently, visiting the GP was viewed as obtaining a service, only necessary when ill and not to obtain health information. The patient/doctor relationship with men treated for prostate cancer was shaped by their ‘cancer journey’.

Many felt that their GP was a poor doctor for not suggesting screening or diagnosing the cancer earlier. A better relationship was exhibited with their specialist who was able to offer treatment and therefore perceived to be more knowledgeable.

“Where are you getting information? Not from a specialist but from an ordinary codger doctor. Because he’s a GP it doesn’t say he’s a specialist or anything in it [prostate cancer].” – PC group

3.5 Barriers to Seeking Health Services

Screening for prostate cancer was not proactively sought because it was viewed as questioning masculinity. Men are traditionally viewed as being physically strong and the notion that something may be wrong, particularly with their reproductive organs, threatened this image. Having a digital rectal examination (DRE) was perceived to be an emasculating experience, requiring men to project a masculine image after having it performed.

“You’re no longer a man mate. I walked into the pub and a guy come up to me and said how does it feel not being a man any more? My automatic reaction was I should have jobbed [hit] him.” – PC group

Despite supporting men’s right to access prostate cancer screening if they choose to, participants in the NPC group were fearful of the prospect of being diagnosed with prostate cancer and what impact that would have upon their lives from a personal, social and professional perspective. It was also believed that there was no reason to visit a doctor unless ill. Doing so was perceived to be flirting with danger and increased the chances of being diagnosed with an otherwise dormant condition.

“I’ve always been a great believer and I think most men are...if it ain’t broke don’t fix it.” – NPC group

3.6 Drivers to Seek and Utilise Health Services

Men in the PC group revealed several methods in which they sought help for their condition. The presence of urological symptoms and/or the need to treat such symptoms acted as a motivator to visit their doctor. Men who had a family member diagnosed with prostate cancer were also more motivated to seek further information on the condition. Men often sought a consultation with their GP at the encouragement of their wives who drew parallels with their screening issues.

“My father died of prostate cancer and I’ve lost two brothers...so I thought well I’ve got to find out about this.” – PC group

Part II – The Nature and Quality of Online Information Regarding PCS

3.7 Search Engine Efficiency

A total of 6690 websites were returned by the search engines and reviewed. Eighty four (1.26%) of these unique websites contained information relevant to prostate cancer screening. The ratio of relevant/total identified websites for each of the search engines were 68/2,750 websites (2.47%) for general search engines, 44/2,667 websites (1.65%) for meta-search engines and 18/1,273 website (1.41%) for medical search engines, **Table 3.2.**

Google and Yahoo, both general search engines, were identified as the most efficient in sourcing relevant websites (7.3%). Vivisimo was the most efficient meta-search engine (5.6%) while OMNI was the most efficient medical search engine (4.7%). Search engine efficiency among the three distinct search engine types (i.e. General, Meta and Medical) was significantly different ($p=0.01$). General search engines were significantly more efficient in sourcing relevant information in comparison to medical search engines ($p=0.02$), as were meta-search engines ($p=0.05$). There was no difference in search engine efficiency between general and meta-search engines ($p=0.48$). There was no significant difference between the quality of website information returned by the type of search engine ($p=0.67$) (i.e. the quality of information on websites returned by general search engines was not better or poorer than those sourced by meta-search or medical). Additionally, there was no significant difference within general ($p=0.93$), meta-search ($p=0.91$) or medical ($p=0.13$) search engines in terms of the quality of website information (i.e. websites identified on Google did not provide a better or poorer quality

of information when compared with Yahoo, Teoma etc.). **Table 3.2** lists the mean (SD) DISCERN score for the various types of search engines.

Table 3.2. Number of relevant and total websites identified across search engines and mean \pm SD quality score.

Search Engine	Number of Relevant Websites (%)	Number of Total Websites	Mean \pm SD DISCERN Quality Rating
General			
Alltheweb	29 (5.3)	550	2.45 \pm 0.74
AltaVista	28 (5.1)	550	2.64 \pm 0.78
Google	40 (7.3)	550	2.49 \pm 0.76
Teoma	27 (4.9)	550	2.56 \pm 0.80
Yahoo	40 (7.3)	550	2.53 \pm 0.75
Unique Websites	68	2750	2.51\pm0.70
Meta			
Excite	26 (4.7)	550	2.69 \pm 0.74
Ixquick	26 (5.4)	483	2.85 \pm 0.78
Profusion	27 (5.0)	543	2.74 \pm 0.81
Surfwax	20 (3.7)	541	2.80 \pm 0.77
Vivisimo	31 (5.6)	550	2.68 \pm 0.79
Unique Websites	44	2667	2.65\pm0.75
Medical			
HealthInsite	1 (1.0)	97	2
MedlinePlus	5 (1.3)	400	3.40 \pm 0.55
HON	11 (2.4)	466	2.55 \pm 0.82
NHS	1 (0.5)	204	2
Omni	5 (4.7)	106	3.20 \pm 0.84
Unique Websites	18	1273	2.66\pm0.84

3.8 Search Strategy

Searches using the term ‘Prostate Cancer’ combined with ‘Diagnosis’, ‘Screening’ or ‘Testing’ returned the greatest number of relevant unique websites, **Table 3.3**.

Conversely searches incorporating specific diagnostic terms, i.e. ‘DRE’ and ‘TRUS’, were least effective. Despite the difference in the number of relevant websites sourced by different search strategies there was no significant difference in the quality of website information strategies ($p=0.23$).

Table 3.3. Number of relevant websites identified by search strategy.

Search Terms	Number of Total Relevant Websites	Mean \pm SD DISCERN Quality Rating
‘Digital Rectal Examination’	21	2.52 \pm 0.75
‘DRE’	0	0
‘Prostate Cancer’	23	2.70 \pm 0.82
‘Prostate Cancer Diagnosis’	35	2.60 \pm 0.88
‘Prostate Cancer Screening’	25	2.72 \pm 0.74
‘Prostate Specific Antigen Testing’	16	2.50 \pm 0.89
‘Prostate Cancer Testing’	22	2.68 \pm 0.78
‘PSA Screening’	17	2.59 \pm 0.62
‘PSA Testing’	19	2.74 \pm 0.73
‘Transrectal Ultrasound’	13	3.07 \pm 0.76
‘TRUS’	9	3.33 \pm 0.71

3.9 Quality of Online Information

The quality of website information on prostate cancer screening was variable. Of the 84 websites assessed for quality, 37 (44%) were rated as providing information of a moderate or better quality (three or above out of five on the DISCERN scale). The quality of information on the remaining websites was of a poor standard. The mean overall quality score for all 84 websites was 2.51 ± 0.74 , **Table 3.4**.

Table 3.4. List of identified websites and their quality rating

Website	DISCERN Rating Score
http://hcd2.bupa.co.uk/fact_sheets/Mosby_factsheets/prostate_cancer.html	2
http://hvlib.integris-health.com/library/healthguide/IllnessConditions/topic.asp?HWID=hw78220	4
http://www.1uphealth.com/health/prostate_cancer_diagnosis_tests.html	3
http://www.50plushealth.co.uk/index.cfm?articleid=1623	2
http://www.aarogya.com	2
http://www.abbottdiagnostics.com/medical_conditions/cancer/prostate_cancer/prostate.htm	3
http://www.accv.org.au/cancer1/patients/prostate/prostate.htm	3
http://www.afud.org/conditions/pd.html	2
http://www.agingwell.state.ny.us/selfcare/cancer/prostate2.htm	3
http://www.alohalabs.com/psa_testing.htm	2
http://www.andrologyaustralia.org/prostate/default.htm	4
http://www.bayviewherc.org/men/symptom_m.html	2
http://www.bccancer.bc.ca/PPI/TypesofCancer/Prostate/default.htm	2
http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Prostate_cancer	2
http://www.body1.com/care/index.cfm/2/19	2
http://www.cancer.ab.ca/ccs/internet/standard/0,3182,3172_428338_428409_langId-en,00.html	3
http://www.cancer.gov/cancer_information/cancer_type/prostate/	4
http://www.cancer.med.umich.edu/prostcan/treatment.htm	2

http://www.cancer.org/docroot/lrn/lrn_0.asp	4
http://www.cancerbacup.org.uk/info/prostate.htm	4
http://www.cancercare.org/ProstateCancer/ProstateCancerList.cfm?c=209	2
http://www.cancerhelp.co.uk/help/?page=2657	3
http://www.cancerlineuk.net/	2
http://www.cancerpage.com/cancers/default.asp?channel=Prostate_Cancer	2
http://www.cdc.gov/cancer/prostate/	3
http://www.claphamhealth.org.uk	2
http://www.cornellurology.com/uro/cornell/prostate/evaluation/psd.shtml	2
http://www.doh.gov.uk/cancer/prostate.htm	2
http://www.e-prostatecancer.net	1
http://www.etmc.org/mens/getcontent.php?SiteID=etmc&docid=/hic/prostate/index	2
http://www.everybody.co.nz/docsq_w/screenpr.htm	2
http://www.exactsciences.com/cic/where_occur/prostate/_index.htm	1
http://www.familydoctor.org/healthfacts/361/	2
http://www.fgcu.edu/chp/deadlytomen/diagnosis.html#Symptoms	3
http://www.health-alliance.com/cancer/Prostate/general.html	3
http://www.healthatoz.com/healthatoz/Atoz/dc/tp/tppsa.html	3
http://www.henryfordhealth-online.org/prostate-cancer-testing-and-treatment.html	2
http://www.holyname.org/health_information_resources/health_manuals/Men/prostate.htm	2
http://www.hopkinsprostate.com/prostateLibraries/plBPH_dre.html	3
http://www.iwon.com/home/health/cancer_overview/0,16398,Prostate+Cancer_Diagnosis,00.htm	2
1	
http://www.labtestsonline.org/understanding/conditions/prostate.html	3
http://www.marinurology.com/articles/cap/learning/trusp.htm	3
http://www.mayoclinic.com/invoke.cfm?id=DS00043	3
http://www.mcghealthcare.org/Canc_02100/Canc_021071.html	2
http://www.medem.com/MedLB/article_detaillb.cfm?article_ID=ZZZXZHOD1KC&sub_cat=36	3

http://www.medicalinfo.com/prostate_cancer.htm	2
http://www.medicinenet.com/Prostate_Cancer/article.htm	3
http://www.menstuff.org/issues/byissue/healthprostate.html#9	2
http://www.moffitt.usf.edu/lcs/screening/prostate.htm	1
http://www.mskcc.org/mskcc/html/9346.cfm	2
http://www.myprostatecancer.com/screening.html	3
http://www.nhsdirect.nhs.uk/SelfHelp/conditions/prostatecancer/prostatecancer.asp	2
http://www.nursingceu.com/NCEU/courses/prostateab/index.htm	3
http://www.oncolink.com/	4
http://www.oncologychannel.com/prostatecancer/diagnosis.shtml	2
http://www.pamf.org/health/guidelines/psa.html	2
http://www.pcacoalition.org/education/whatis.php	2
http://www.pcaw.com/	3
http://www.peoplelivingwithcancer.org/	2
http://www.prostate.com/	2
http://www.prostate.com.au/introduction.html	4
http://www.prostatecanada.net/	2
http://www.prostate-cancer.org.uk	3
http://www.prostate-cancer-institute.org/	2
http://www.prostatecancerlaw.com/prostate-cancer-diagnosis.shtml	2
http://www.prostatecancernj.com/	2
http://www.prostatecanceruk.org	3
http://www.prostatedisease.org/	2
http://www.prostatedoctor.com	3
http://www.prostatehealth.org.au/	4
http://www.prostateinfo.com/	3
http://www.prostate-research.org.uk	2

http://www.slucare.edu/patient/library/articles/671.shtml	2
http://www.stjohnsmercy.org/mmg/mmghealthinfo/adults/healthmaintenance/PSAScreening.asp	3
http://www.texmed.org/has/pin/car/healthy_ending_0302_prostate_cancer.asp	2
http://www.thecancer.info/prostate/wynk	2
http://www.thedoctorwillseeyounow.com/articles/cancer/prostate_5/	3
http://www.upmccancercenters.com/cancer/prostate/pfv/dre.html	4
http://www.uro.com/prostate.htm	2
http://www.urologyhealth.org/adult/index.cfm?cat=05&topic=250	3
http://www.urologyteam.com/education/prostate_diseases.php	2
http://www.urosoc.org.au/info/screeningprostate.html	3
http://www.vmmc.org/dbProstateCancer/sec39165.htm	3
http://www.wmfurology.com/pcaweb.htm	2

3.10 Website Characteristics

A set of website characteristics were defined in order to detect whether their presence, or absence, affected the quality of website information, **Table 3.5**.⁵⁷ Websites that offered a referral link to other relevant information and provided a citation of the evidence on their website were more likely to provide a significantly better quality of information.

Conversely, websites that offered a direct service to the consumer were more likely to provide information of a significantly poorer quality. Although not statistically significant, websites that offer a statement regarding the authorship of the information may offer better quality information than websites that do not ($p=0.08$). Similarly, websites designed to provide information specifically to the consumer may not provide as good a quality of information when compared to websites that aim to provide information that is relevant to both health professionals and consumers ($p=0.06$). It has been stated that the same set of quality standards that helps users of medical information navigate that in print format (i.e. authorship, attribution, disclosure and currency) should apply in the digital world.⁴⁸ When compared to these characteristics 14 (17%) websites provided authorship, 13 (15%) provided attribution, 32 (38%) provided disclosure and 60 (72%) provided relevant currency details. However, none of these criteria were significantly associated with information of higher quality.

Table 3.5. Parameters of website quality scores relating to presence/absence of website characteristics.

Website Characteristic	Presence of Website Characteristic	Absence of Website Characteristic	Quality Score of Websites with Characteristic	Quality Score of Websites without Characteristic	P-Value
Target group identified	38	46	2.58±0.72	2.45±0.75	0.56
Sponsoring identified	32	52	2.50±0.72	2.52±0.75	0.94
Membership availability to users	23	61	2.52±0.67	2.51±0.77	0.96
Direct services available to users	43	41	2.19±0.55	2.85±0.76	0.0001 [#]
Links to the site from other sites	60	24	2.57±0.72	2.38±0.77	0.30
Currency of information recognized	60	24	2.58±0.72	2.33±0.76	0.15
Updating of information recognized	7	77	2.57±0.79	2.51±0.74	0.98
Authorship recognition	14	70	2.86±0.95	2.44±0.67	0.08
Referral links to other resources	66	18	2.61±0.74	2.17±0.62	0.04 [#]
External approval of the website	23	61	2.52±0.90	2.51±0.67	0.97
Citation/referencing of evidence for website information	13	71	3.54±0.52	2.32±0.60	0.0001 [#]

Values are total number of websites with characteristics present/absent and mean ± SD DISCERN quality score. (# - significant at 0.05).

3.11 Commissioning Agencies

A variety of agencies were identified as providing website information on prostate cancer screening, **Table 3.6**. Healthcare organisations and general health portals (generic websites that provide healthcare information on a broad range of topics) provided the greatest number of websites offering relevant information. These websites commonly provide a short synopsis of information. Conversely websites specifically focused on providing information, and/or direct products/services, regularly provided a greater depth of information.

Table 3.6. Number of websites according to the nature of the website's commissioning agency.

Nature of Commissioning Agency	Number of Websites
General health portal	15
Healthcare organisation	15
Healthcare organisation offering related products/services	7
Specific site relating to cancer and/or prostate cancer not offering products/services	6
Specific site relating to cancer and /or prostate cancer offering related products/services	6
General health site offering products/services	6
Medical information/support organisation	5
Private health professional site offering products/services	5
Prostate cancer agency/organisation	5
Cancer society/association	4
Medical association/organisation	3
Men's health information service/promotion	2
University institution	2
Law firm	1
Medical education resource	1
Prostate cancer site - personal patient's experience	1

3.12 External Agency Approval

Thirteen different external agencies offered a seal of approval from an external agency for information provided by websites, **Table 3.7**. As previously observed there was no significant difference in the quality of information in websites that were approved from an external agency compared to those websites that were not. The HON code of website approval is accepted as the main source of external approval a website can receive when providing medical/healthcare information online. To obtain such approval a website must agree to abide by set principles defined by ethical standards. Despite the governance of this standard it was identified that websites approved by the HON did not provide a significantly better quality of information in comparison to websites externally approved by other agencies (p=0.48).

Table 3.7. Number of websites approved by an external agency.

External Agency	Description of the Agency’s Seal of Approval	Number of Websites
Apex Award	‘The APEX award is an annual competition for writers, editors, publications staff and business and non-profit communicators for providing excellence for web site content and writing. It is judged by “Writing That Works” - an online business communications report.’	1
Associations Advance America	‘The Associations Advance America Awards are presented in recognition to associations that propel America forward with innovative projects in skills training and development; ethical, technical or professional standards; economic development; business and social innovation; information and knowledge creation; public education and information; civic and community volunteer activities; and citizenship and democracy enhancement.’	1
Bobby	‘Bobby is a comprehensive web accessibility software tool designed to help expose and repair barriers to accessibility and encourage compliance with existing accessibility guidelines. It offers prioritized suggestions based on the Web Content Accessibility Guidelines provided by the World Wide Web Consortium’s (W3C) Web Access Initiative.’	1

Financial review – internet award	No information is available.	1
HealthInsite	‘HealthInsite is a Commonwealth Government of Australia initiative, funded by the Commonwealth Department of Health and Ageing. It aims to improve the health of Australians by providing easy access to quality information about human health.’	1
Internet crystal mark 017	No information is present	1
Online A category winner	‘This Award is awarded by the Public Health Association of Australia for the best online news, special features and/or discussion forum on a public health issue.’	1
RSAC (Recreational Software Advisory Council)	‘RSAC no longer exists. In 1999 it was "folded into" a new organization, the Internet Content Rating Association (ICRA). The original aims of RSAC were to protect children from potentially harmful content while preserving free speech on the internet.’	1
Scientific American 2002 Sci Tech Web Awards Golden Web Award	‘Scientific American, both a print and online magazine, brings its readers unique insights about developments in science and technology. Their Golden Web awards list their 50 favourite sites in across different scientific categories.’	1
W3C (World Wide Web Consortium)	‘The W3C develops interoperable technologies (specifications, guidelines, software, and tools) to lead the Web to its full potential. W3C is a forum for information, commerce, communication, and collective understanding.’	1
WebAward	‘The Web Marketing Association was founded in 1997 to help set a high standard for Internet marketing and corporate web development on the World Wide Web.’	1
TRUSTe	‘Websites displaying the TRUSTe Privacy Seal are committed to abiding by a privacy policy that gives users notice, choice, access, security and redress with regard to their personal information.’	3
HON (Health on the Net)	‘HON aims to guide the growing community of healthcare consumers and providers on the World Wide Web to sound, reliable medical information and expertise.’	20

3.13 The Role of Domains

Both the *.com* and the *.org* domains were the most commonly sourced website domains,

Table 3.8. Websites using the *.gov* domain provided the highest quality of information scores. Websites emanating from the *.com* and *.org* domains provided 74% and 85% of websites that provided a referral link to other resources and a citation of evidence on their website. Conversely only one website emanating from an *.edu* domain provided a referral link to other resources and none provided a citation of their evidence. Conversely 77% of websites that offered a direct service were derived from a *.com* or *.org* domain.

Table 3.8. Number of websites identified according to domains.

Domain	Number of Websites	Mean \pm SD DISCERN Quality Score
<i>.co</i>	4	2.25 \pm 0.25
<i>.com</i>	34	2.65 \pm 0.73
<i>.edu</i>	4	2.0 \pm 0.82
<i>.gov</i>	4	2.75 \pm 0.96
<i>.net</i>	4	1.75 \pm 0.25
<i>.org</i>	29	2.55 \pm 0.74
<i>other</i>	5	2.40 \pm 0.55

Of the websites against screening for prostate cancer, the majority emanated from the .gov domain. Conversely websites from the .com domain were the greatest in number in favour and promoting screening for prostate cancer, **Table 3.9**.

Table 3.9. Website recommendation regarding screening according to domain.

Domain	Recommendation			
	(A) Against PCS	(B) None – only provides advantages & disadvantages of PCS	(C) Discussion with health professional	(D) In Favour of PCS
<i>.co</i>	2	2	0	0
<i>.com</i>	0	4	8	22
<i>.edu</i>	0	0	0	4
<i>.gov</i>	1	1	2	0
<i>.net</i>	0	2	1	1
<i>.org</i>	5	4	8	12
<i>other</i>	1	0	3	1
Total	9	13	22	40

3.14 Comparison of Online Information to the Available Evidence

A variety of recommendations regarding prostate cancer screening were issued on websites despite the lack of a clear consensus on guidelines and recommendation in the literature, **Table 3.10**. Websites that recommended against PCS and those advising the consumer to discuss PCS with their health professional had a significantly higher quality of information score when compared to websites that provided no direct recommendation but listed the benefits and risks of screening ($p=0.02$).

Table 3.10. Number of websites according to type of recommendations made.

Recommendation	Total Number of Identified Websites	Total Number Providing Evidence Supporting the Recommendation	Mean \pm SD DISCERN Score
(A) Advises a recommendation against PCS	9	3	2.89 \pm 0.78
(B) Lists the advantages and disadvantages of PCS but provides no direct recommendation	13	2	2.08 \pm 0.49
(C) Advises the consumer to discuss PCS with their health professional	22	4	2.77 \pm 0.81
(D) Advises a recommendation in favour of PCS	40	4	2.42 \pm 0.68

Websites recommending against PCS

Nine websites recommended against PCS. All provided an overview on prostate cancer covering issues including the incidence, potential risk factors, diagnosis and treatment options available to those diagnosed with prostate cancer. The depth of information ranged from websites providing a synopsis of the mentioned issues to those providing detailed information in a comprehensive format.

Seven of the nine websites highlighted the controversial nature of PCS stating the current conflict of evidence surrounding it, *'...scientific evidence is insufficient to determine if screening for prostate cancer reduces deaths or if treatment of disease at an early stage is more effective than no treatment in prolonging a man's life...'* and, *'There is no conclusive evidence that screening for prostate cancer would reduce the death rate from prostate cancer.'* Despite such statements only two websites cited examples of this clash in viewpoint, providing excerpts from reports such as the US Preventive Task Force, American Cancer Society and the American Urological Association to further illustrate and validate their statement.

Another common theme that emerged from the websites revolved around the potential for increased anxiety that screening may present to men and the impact that diagnosis or potential treatment may have upon a patient's quality of life. *'Many men with prostate cancer do not have symptoms. Prostate cancer grows slowly in many older men and they are unlikely to die from it. These men do not really need treatment. The treatment has side effects and could cause more problems than their cancer.'*, and *'... by diagnosing*

and treating cancers that might not need to be treated, the risk of reduced quality of life from treatment complications may be higher than if they were not screened.'

In effect the information presented on these websites attempts to discourage men from screening by stating that since no definitive evidence exists to suggest that screening may be beneficial, there is no clear advantage for men to be screened. Three websites cited health technology reports and reviews, while two websites supported their recommendations against screening by citing evidence from a recognized peak body/cancer society. These websites, while recommending against population screening of asymptomatic men, did state that men do have the right to be screened for prostate cancer should they wish to do so but should be fully informed of all the facts to make a truly informed decision. All of the references cited were with respect to the issue of PCS.

Websites providing no direct recommendation

Thirteen websites promoted 'neutral' information, i.e. did not provide a distinct recommendation either for or against PCS, providing information in a manner ranging from shorter point form information guides to those that provide greater discussion on the topic. Typically these websites provide information in a non biased style providing a general overview of the topic, covering issues such as anatomy, function, incidence, associated symptoms, preventative measures, diagnosis/screening and treatment regimes.

These websites recognize the controversial nature of the topic and the lack of a definite evidence base. *'Whilst breast cancer screening clearly saves lives, the case for prostate*

cancer is not so clear. This is partly because at present there is no test that is accurate enough to be reliable.' Accordingly the websites attempt to act as a supplementary information source to further inform the reader, with particular emphasis on the tests that may be used in the screening/diagnostic process.

Typically websites provide information covering all three types of diagnostic tests used, the DRE, PSA and TRUS biopsy, with most providing a greater amount of detail on the DRE and PSA. In keeping with the unbiased nature of the information, both the advantages, *'The benefit of finding a prostate cancer at this early stage is that it might be possible to remove the cancer'*, and disadvantages, *'...that this [PCS] mightn't completely rule out cancer. So you may need to have further tests some time afterwards.'*, of screening are published. A greater emphasis on what the patient may expect in terms of the procedure of the test is also provided in these websites. This is often represented in the forms of both a diagram of the procedure/instruments used and a written explanation. *'This test [PSA] can be performed in a clinical laboratory, hospital or physician's office and requires no special preparation on the part of the patient. A tourniquet or rubber strap is tied around the upper arm to mildly restrict the flow of blood and keep blood in the vein.'*

Of the thirteen websites, two provided a citation of their evidence that included health technology reports and reviews. These references specifically related to the issues surrounding PCS. No references were cited in sections of the websites that described the screening tests and procedures.

Websites promoting discussion with a health professional

The majority of the 22 websites promoting informed discussion about PCS by men with their health professional provide information in a detailed or slightly abridged format. Included in their discussions on the topic are themes incorporating the anatomical and physiological role of the prostate, the prevention of prostate cancer, associated symptoms, diagnosis procedures and treatment regimes and their implications. Only two of the websites in this set provided this information in a short point summary format.

Websites typically acknowledged the debate within the medical community surrounding the use of screening for prostate cancer citing views pro-screening, *'Advocates cite the large number of patients who die of the disease as sufficient justification to initiate screening programs, arguing that lives can be saved by early detection and treatment'*, and against screening, *'Until better data become available, such as trends in prostate cancer mortality and results from ongoing clinical trials, the debate about screening for prostate cancer cannot be resolved.'* Six websites cited recommendations from medical societies/organisations to illustrate these conflicting viewpoints.

The information was presented in an unbiased format, intending to inform the reader about the topic of prostate cancer along with the issues implicated with its screening. *'Prostate cancer can be aggressive...or it may be slow growing and stay in the prostate causing few if any problems.'* Websites tended to provide more information on the different procedures (i.e. DRE, PSA and TRUS) available in the screening process, what

to expect during the procedure itself and the interpretation of any results. *'If your doctor finds any abnormalities in the texture, shape or size of your gland [during the DRE], you may need more tests.'* Websites acknowledge that none of the tests used in the screening for prostate cancer are perfect, and recommended that patients must keep this in mind when deciding on whether to be screened or not. *'...PSA tests results may be abnormal in men who do not have prostate cancer...yet it is possible to have normal PSA results and still have prostate cancer'*, and *'While screening can result in the earlier detection of prostate cancer, scientific studies have not shown that it results in improved survival.'*

These websites have the intention of informing the reader about the issues surrounding prostate cancer and screening. As such they do not give a recommendation either way but rather leave the onus up to the reader to consult their health professional in reaching a shared decision regarding screening. *'The decision whether to have screening for prostate cancer involves several considerations and is one you should discuss with your doctor'* and *'Patients should discuss their situation with their doctor and work together to make a decision'*.

Of the 22 websites, thirteen cited a medical society/organisation to illustrate the need for discussion with a health professional in reaching a decision about prostate cancer screening. Of those websites providing such a citation, only four cited evidence for the information presented on their website. Three of these were health technology reports and reviews relating to specifically to issues associated with screening. The remaining website cited over 20 articles, all level IV evidence. It did cite one level II and two level I

articles, however the content of these articles were related to issues involving treatment of prostate cancer and not screening.

Websites recommending PCS

Forty websites recommended screening for prostate cancer and typically provided a complete overview on the topic. Issues including anatomical/physiological significance of the prostate, signs/symptoms, potential risk factors, screening and diagnostic procedures and treatments were discussed using various formats. More than half of the websites provided information in either a short summary or succinct format, while the remaining websites providing information in a more detailed manner.

Whilst covering the previously mentioned topics, the majority of sites tended to dedicate a greater amount of information to issues regarding screening for prostate cancer.

Thirty-seven websites identified the current controversy encompassing the justification of screening men, '*...prostate cancer screening is probably the most controversial issue in the field of preventive medicine*'. Websites also made mention that this controversy can be attributed to the lack of genuine research findings in the area, '*...the lack of evidence does not mean prevention [PCS] is not beneficial, it just means that they have not performed enough research in the area.*' One website illustrated this by citing recommendations by medical societies and peak bodies who are in favour (American Cancer Society (ACS), American Urological Association (AUA)) and against (US Preventive Services Task Force (USPSTF) screening for prostate cancer.

Despite the controversial nature of PCS, two websites discounted the controversy and equated the process of PCS with that of mammographic screening for breast cancer in women, *'early detection and treatment for prostate cancer, like breast cancer, is the key to survival...the earlier it's treated, the better.'* Few websites acknowledged the impact of the PSA test on the rise in incidence of prostate cancer in the early 1990's and its influence on mortality rates, *'Since the use of early detection tests for prostate cancer became relatively common (about 1990), the prostate cancer death rate has dropped. But it has not been proven that this is a direct result of screening. Studies are underway to try to prove that early detection tests for prostate cancer in large groups of men will lower the prostate cancer death rate.'*

All but four of the websites provided information on the DRE, PSA and TRUS methods of screening, with an additional six websites providing further information on associated tests that may also be used in the screening process, such as bone scans. Half of the websites noted the implications and limitations associated with different screening techniques when describing both the advantages and disadvantages associated with each screening intervention. For example, when describing the DRE websites often noted that it is one of the first tests health professionals may offer due to the 'simple' nature of it. Disadvantages of the DRE also cited included such statements as, *'this exam is not complete because it fails to give the examiner the ability to feel the front portal of the prostate'*. Websites tended to provide more information on the use of the PSA test in the screening procedure, also acknowledging its strengths and weaknesses, *'The PSA test is considered twice as reliable as rectal exam in the diagnosis of early prostate*

cancer...however it is not infallible; a man's PSA level tends to rise when the prostate becomes enlarged, but the enlargement may or may not be due to cancer'.

All but three of the websites provided information on prostate cancer screening in an unbiased format, stating both sides of the argument, *'the theoretical advantage of finding cancer early, before they cause symptoms, is that early cancer are less likely to have spread and may be easier to treat. But the disadvantage of screening is that it often leads to unnecessary additional diagnostic procedures.'* The three remaining websites provided information as well as incorporating their opinion as to why men should be screened for prostate cancer. One of these websites was produced by a 'prostate cancer survivor' whose statements included, *'Wonder what that's all about? When early detection clearly saves lives, who gains from not being tested except those who know they don't have prostate cancer. And, without symptoms, who knows? Maybe the doctors and hospital and funeral homes gain? Families sure don't. Gives one something to think about!'* The other two websites provided direct services relating to prostate cancer, either screening and/or treatment programs, and thus had the potential to directly benefit from any readers influenced by their stance, *'Prostate cancer is most curable when it is detected early. Our comprehensive approach to diagnosis and treatment begins with an evaluation to detect the disease in its earliest stages and to characterize it thoroughly.'* Only two websites provided any reasoning relating to their recommendation, *'We advocate screening for prostate cancer in men who have a high likelihood of being alive in ten years'.*

Of the 40 websites, 15 provided a direct statement in the support of prostate cancer screening, *'Men over the age of 50 should be screened once every year. African American men or any with a family history of prostate cancer should begin these annual exams at age 40'*. However, only two of these websites cited references for this recommendation, or the information contained on their website. These references were comprised of evidence consisting of books, review articles and health technology reports. The remaining websites either made a statement based on a medical society/peak body, or referencing as such, *'They⁹ recommend annual screening tests begin at age 50 including a digital rectal examination (DRE) and serum prostate specific antigen (PSA) test... men who fall into high risk categories (i.e. strong family history, African American males) should begin screening before age 50, with the AUA recommending initiation of an early detection program at age 40 and ACS suggesting initiation of testing at age 45.'* Similarly only two of these websites cited any references in support of information contained on their website.

Summary

The differing viewpoints represented in the current literature regarding prostate cancer screening is reflected in the information available on the Internet. Online information ranges from websites whose viewpoints are directly in favour of screening, those opposing screening and those providing a service so the consumer may be more informed when potentially discussing their options with their health professional. The lack of a definitive evidence base available at the time of this assessment is reflected in the online equivalent. This lack of synergy between medical research and web based patient

information is further highlighted in the lack of evidence citation by websites, with 36% of websites citing a medical organisation/peak body in providing their recommendation and 15% providing a citation of evidence for their information.

Despite the lack of consultation to the available evidence, websites did recognize the controversial nature of the topic and potential for conflicting viewpoints. Although websites provided information on the broad topic of prostate cancer and its screening, the emphasis was typically on the screening procedures and their implications. The deregulated nature of the Internet makes it more prone as a medium to the publishing of biased information. Despite this only a small proportion of websites provided information in a biased manner, these being websites recommending or advocating the use of prostate cancer screening. Alternatively websites recommending against screening provided information in an unbiased format (i.e. presented both sides of the argument) whilst also providing some sort of citation in the justification of their stance.

Discussion

4.1 Overall Findings

Part I – The Consumer Perspective on PCS

Participants diagnosed with prostate cancer expressed similar attitudes about prostate cancer screening to men with no previous diagnosis. Several barriers were identified by participants as preventing men from seeking information and support on screening for prostate cancer. A lack of health knowledge, limited access to health information, poor patient/doctor communication and the influence of psycho-social masculine attitudes contributed to a poor understanding of the issue. Despite the presence of such barriers, all participants collectively supported widespread community screening for prostate cancer.

Participants in this study demonstrated a need to acquire health information to facilitate a better understanding of health issues, findings also shared by other studies.^{27 30} Doctors have traditionally been the main source for medical information for patients. The presence of psychosocial masculine attitudes and a poor patient/doctor relationship discourages men from obtaining health information and assistance. Encouraging doctors to engage with men and develop a stronger relationship may promote greater discussion of the implications of screening for prostate cancer. Few participants in this study chose to adopt a shared approach with their doctor. These findings differ with other studies that have identified men preferring to adopt a more shared approach to decision making regarding prostate cancer screening.^{67 68}

Men in this study reported having a poor relationship with their doctor. Promoting a shared approach to decision making may improve this relationship and increase the value

men place on information received by their doctors. Previous studies have demonstrated that providing men with information on prostate cancer screening increases knowledge.⁶⁹⁻⁷¹ While adopting such an approach would be valuable to both parties, time constraints placed on doctors may negate its widespread implementation in general practice. A more realistic approach may be to promote the doctor as a 'gatekeeper' of health information.

The widespread promotion and acceptance of men's health issues is still in its infancy. Current education strategies and programs appear to increase men's awareness of health issues but fail to encourage men not to rely on clinical symptoms as their primary motivator for utilising health services. Targeting awareness campaigns to women in a bid to act as a surrogate provider of information may be beneficial however such a system can only succeed if the man has a willing partner. Increasing men's awareness to accessible sources of health information may be the primary method of whittling away the influence of masculine attitudes and encouraging men to take greater responsibility for their health.

Men obtain health information from a variety of sources.²⁷ Promoting quality information of men's health issues through the Internet may provide men with a non-threatening environment in which to access information and encourage greater interest in their health. Embracing this technology allows men to anonymously access information at their convenience. It also promotes the disembodiment of psychosocial masculine attitudes often exhibited during face to face contact. Overcoming such attitudes may also reduce the fear, anxiety and confusion often associated when discussing any form of

cancer. Utilising this technology may be particularly pertinent when encouraging greater awareness and appreciation of men's health issues in younger men, for whom the Internet is a common function of life.

Findings derived from qualitative research techniques may offer a richer content than longer quantitative studies but it may be argued that such results are not as generalisable. Although this study recruited volunteers from a variety of socio-economic backgrounds, the beliefs expressed may be more common in some populations than others. During the recruitment period a variety of prostate cancer awareness campaigns were advertised. Therefore, the impact of selection bias must also be considered when conducting studies with volunteers. Similarly, the 'cancer journey' experienced by men diagnosed with prostate cancer may have shaped their views on the issue and potentially led to recall bias.

Part II – The Nature and Quality of Online Information Regarding PCS

Both general and meta-search engines are significantly more efficient than medical search engines in sourcing relevant online information on prostate cancer screening. Additionally, websites returned by medical search engines showed no significant difference in the quality of information in comparison to those sourced by general and meta-search engines. Searches incorporating the term 'prostate cancer' in association with 'diagnosis', 'screening' or 'testing' were more likely to identify relevant online information. The quality of online information available on prostate cancer screening was variable, with the majority of websites providing information of a poor quality. Despite

this variation it was identified that websites that had referral links to other relevant resources and provided a citation of evidence were more likely to contain a significantly better quality of information. In contrast websites that offered a direct service (e.g. a screening program for prostate cancer) were more likely to contain information of a significantly poorer quality. A variety of recommendations were offered by websites regarding the merits of prostate cancer screening, with the majority recommending screening for prostate cancer.

Consumers are turning to the Internet as a medical resource in order to take a greater role in the decision-making processes. In the absence of directly accessing websites, through referral or recommendation, consumers will turn to using search engines in order to locate online medical information. Although search engines can locate websites they do not guarantee that the returned website information will be relevant or valid. Irrelevant websites may often obtain a higher ranking on search results. This can result from webmasters manipulating the characteristics of the website to achieve a higher ranking (e.g. following links from other webpages to source new pages, repeating keywords in metadata or by payment of website placement to specific organisations).⁷²⁻⁷⁵ More resources are being spent on creating new and refining old search engines in an attempt to provide the most efficient means of sourcing relevant information from a greater index of websites. Medical search engines have been designed to provide a specific index of online medical information, ostensibly offering a more precise return of relevant websites than the larger indexing general and meta-search engines. Despite the substantial undertaking by commercial and government entities, this study has identified that the

construction of medical search engines does not provide a more specific index of medical websites containing relevant information on prostate cancer screening. General and meta-search engines were significantly more efficient than medical search engines in sourcing relevant online information and that information was of equal validity. Google and Yahoo, both general search engines, provided the most efficient searches when sourcing for online information for prostate cancer screening. Both of these search engines are recognised as providing a large index of websites available on the Internet. This suggests that performing a search on an engine with a larger index may provide a more efficient return of relevant websites than one conducted on a search engine with a small index. These findings also suggest that medical search engines are no better than general or meta-search engines at sourcing medical information on the Internet, substantiating findings from previous studies.^{57 76}

Medical search engines are marketed as providing a more specific index of websites that contain medical information. This infers that websites returned from medical search engines will be more relevant and be of a higher quality, or reliability, in terms of information rather than those that might be returned by larger less specific indexes such as general and meta-search engines. This study identified that the quality of information did not differ across websites that were identified by general, medical or meta-search engines. This finding has also been paralleled in a study on the male reproductive health topic of androgen deficiency in the ageing male.⁵⁷ It has also been identified that consumers and health professionals alike prefer to use general rather than medical search engines when searching for medical information on the Internet.⁷⁷ Since the quality of

website information does not differ according to which search engine is used, it may be of greater community benefit if the resources allocated to developing medical search engines are applied to increase consumer awareness with regard to the quality issues associated with medical information obtained on the Internet.

Medical issues that lack a definitive evidence base are more likely to have this uncertainty reflected in the quality of information available on the Internet. This study has shown that disagreement within the medical literature, and a lack of high quality evidence, is reflected by the vast quantity of poor quality information published on websites on the Internet. This trend has also been recognized in the controversial men's health topic of androgen deficiency in the ageing male.⁵⁷ Conversely the quality of online information relating to the treatment of erectile dysfunction by Sildenafil (Viagra), has been identified to be of a good quality.⁵⁵ Unlike prostate cancer screening and androgen deficiency in the ageing male, clear recommendations and agreement exist in the medical literature and within the community regarding issues involving erectile dysfunction.⁷⁸ Although the distinction of an evidence base with regard to prostate cancer screening is not clear, it is discouraging to observe that less than a third of websites provide any form of evidence citation to justify or validate the information presented on their websites. This divide highlights the tendency of websites not to use or acknowledge the use of evidence either due to issues regarding a lack of vigilance, quality governance or outright refusal.

Few Internet users seeking medical information have both the expertise in information retrieval and the medical knowledge necessary to evaluate the validity of medical information published online. Quality codes, rating tools and approval systems have all been created in a bid to provide a user-friendly system that may assist users in forming a valid opinion based on online medical literature. However, their use may be limited by consumers who are unaware of their existence or unforthcoming in their use. This may be due to time restrictions, unfamiliarity with the requirements needed to use quality rating tools or hesitation in the worth or validity of external approval systems or codes.

Independent third party rating systems attempt to provide an objective appraisal of information in order to guide the user to the most appropriate and reliable information.

These systems often breakdown as they can only assess website information from a particular point in time. Quality rating tools may raise consumer awareness about quality issues however they can not specifically address the evidence that underpins the issue. This leaves the consumer virtually unaided in attempting to reach an informed decision.

The unregulated nature of the Internet does not force website publishers to adhere to quality standards as required by traditional media sources. It has been suggested that the onus may lie with the health professional to inform and educate consumers in their search for reliable medical information online.⁵⁸ Forcing health professionals to act as information gatekeepers may be unrealistic given the time restrictions encountered when providing a complete consultation. Given that the Internet is a free form source of information an alternative may be for consumers to embrace the autonomy and responsibility of searching for online medical information through further education of

quality issues and their implications, and to incorporate this with consulting the health professional in shared decision making.

Silberg et al highlighted the presence of authorship, attribution, disclosure and currency as pillars for quality online information.⁴⁸ Assessing, or being aware, of particular individual website characteristics may offer consumers with a greater insight into the quality of the website information. Websites providing information on PCS that have referral materials and citation of evidence may be of more worth, whilst those offering a direct service may carry less weight, as consumers recognise the implications of the presence and absence that these characteristics represent with regard to quality. These findings support similar results that suggest that website characteristics such as providing online referral materials and a direct service are quality indicators of good and poor quality online information respectively.⁷⁹ An increased sensitivity to such aspects creates a greater consumer consciousness regarding the manner in which the information is presented and the implications of any biases contained within it. Increased awareness of website characteristics enables consumers to formulate a quick opinion on the quality of the information. This judgment can be further validated with the use of quality rating tools, or compared to recommendations made by external third parties. The liberated nature of the Internet can also be utilised as information sourced from one website can easily be cross referenced against that offered by another.

A greater appreciation of these characteristics may cause closer examination of apparent discrete characteristics. Greater restrictions on the purchasing of Internet domains allows

consumers to confidently examine the motives of the website publishing the medical information, i.e. websites with an .edu domain genuinely emanate from educational institutions while .org and .com/co are organisations and entities with a commercial interest. However users must be made aware that although a website may have commercial interests it does not guarantee that the information presented is not better than those originating from education or government entities. As was identified in this study, only one in four websites emanating from an educational institute provided referral links to other resources and none provided a citation of evidence supporting their published information. Recognising the country code domain may also aid consumers in identifying whether the information presented on the website is applicable and valid in their residing country. This has particular significance when the availability of screening tools or therapies is limited in certain countries. By raising the importance of such characteristics the consumer is to a certain extent armed with the skills to ‘critically’ appraise the information presented to them. This process in combination with quality rating tools, codes and external agency recommendations can provide the resources necessary to evaluate medical information published on a dynamic medium.

The Internet’s primary aim as a communications network is to relay information in an unrestricted format. Its impact upon the health services can be identified through the promotion of information exchange and an increased degree of self care management by enabling informed decision making. The very nature of the Internet and the broad range of interests it represents should encourage consumers to maintain a healthy level of scepticism about information that is presented to them. Ideally the Internet should be used

as a secondary source of medical information for consumers wishing to take a greater role in their health outcomes, which incorporates utilizing the time spent with their health professional most efficiently.

The Internet is a constantly evolving dynamic medium. These results can only represent a snap shot of the information available on prostate cancer screening at a given point in time. Given the controversial nature of the topic it would not be appropriate to extrapolate the finding that medical search engines are no more efficient than general or meta-search engines in sourcing online information on health topics unrelated to prostate cancer screening or men's health and this study should be repeating in other, better researched areas of health care. Upcoming years will see the completion of various randomised trials on prostate cancer screening. Data made available from these trials will offer a higher quality of evidence than what currently exists. Future research could identify whether this information, resulting in a possible change in the medical literature, is incorporated online and what influence it has upon the quality of online information.

Several issues need to be addressed before the Internet can be used as a health resource.

Most users do not have the ability to locate and identify quality health information efficiently,^{31 33 77} difficulties that were also mentioned by men in this study. There is a real possibility that users may access inaccurate or misleading information which may negatively impact upon knowledge, attitudes and decision making processes.

Subsequently, the responsibility may fall back onto health professionals to act as the

gatekeeper of online information and guide men in their search for credible information efficiently.

Conclusions and Recommendations

5.1 Conclusions

- Although men have the ability to utilise a variety of information sources to increase their health knowledge, a significant majority remain uninformed about health issues
- The presence of psychosocial masculine attitudes impacts negatively on the manner in which men converse with their doctor, utilise health services and contemplate their well being
- Health professionals should not encourage or discourage men to be screened for prostate cancer given the current equipoise about its efficacy
- The Internet is a potential resource men can use to access health information, including that on prostate cancer screening
- General and meta-search engines are more likely to source relevant websites offering information on prostate cancer screening than are medical search engines
- The overall variation in quality of online information available on prostate cancer screening may be representative of the lack of a consensus regarding recommendations and guidelines within the current medical literature

5.2 Recommendations

Consumer confidence in sourcing quality information from the Internet to supplement any decisions regarding their health may be attained by increasing consumer awareness.

This may be achieved through better understanding of;

- The use of different search engines and their role in sourcing information
- The application of quality pillars and the impact of the presence/absence of specific website characteristics
- Consumer rating tools such as DISCERN to reach an independent assessment of website quality

This may be facilitated through the availability of this information through an 'Internet User's Guide', which may be distributed in a CDROM format or made available through the Internet to consumers and health professionals.

Future research could identify;

- How educating men to access quality information on the Internet affects their satisfaction with information sourced
- How health information presented on the Internet affects patient knowledge and health outcomes in comparison to traditional sources of patient education such as video and written information

References

1. Brawer M. Screening for prostate cancer. *Seminars in Surgical Oncology* 2000;18:29-36.
2. Mazhar D, Waxman J. Prostate cancer. *Postgraduate Medical Journal* 2002;78:590-595.
3. van dan Crujisen-Koeter I, Wildhagen M, De Koning H, Schroder F. The value of current diagnostic tests in prostate cancer screening. *BJU International* 2001;88:458-466.
4. Neal D, Donovan J. Prostate cancer: to screen or not to screen? *Lancet Oncology* 2000;1:17-24.
5. Neal D, Leung H, Powell P, Hamdy F, Donovan J. Unanswered questions in screening for prostate cancer. *European Journal of Cancer* 2000;36:1316-1321.
6. Makinen T, Tammela T, Stenman U, Maattanen L, Rannikko S, Aro J, et al. Family history and prostate cancer screening with prostate-specific antigen. *Journal of Clinical Oncology* 2002;20:2658-2663.
7. Chan J, Stampfer M, Giovannucci E. What causes prostate cancer? A brief summary of the epidemiology. *Seminars in Cancer Biology* 1998;8:263-273.
8. Pienta K, Esper P. Risk factors for prostate cancer. *Annals of Internal Medicine* 1993;118:793-803.
9. Smith RA, Cokkinides V, Eyre HJ, American Cancer S. American Cancer Society guidelines for the early detection of cancer, 2003. *Ca: a Cancer Journal for Clinicians*. 2003;53(1):27-43.
10. American Urological Association: Available at; <http://www.auanet.org> Accessed 5/9/2003.
11. Ferrini R, Woolf S. American College of Preventive Medicine Practice Policy. Screening for prostate cancer in American men. *American Journal of Preventive Medicine* 1998;15:81-84.
12. American Medical Association: Available at; <http://www.ama-assn.org> Accessed 6/4/2003.
13. Urological Society of Australasia: Available at; <http://www.urosoc.org.au> Accessed 6/4/2003.
14. US Services Preventive Task Force. Screening for prostate cancer: Recommendations and rationale. *American Family Physician*. 2003;67(4):787-92.
15. Schersten T, Baile M, Asua J, Jonsson E. Prostate cancer screening. Evidence synthesis and update. Statement of Finding. Osteba.: Vitoria-Gasteiz: Dpt. of Health Basque Government. Basque Office for Health Technology Assessment, 1999.
16. Anonymous. Screening for prostate cancer. American College of Physicians. *Annals of Internal Medicine*. 1997;126(6):480-4.
17. Canadian Urological Association; Guidelines for early detection of prostate cancer.: Available at <http://www.cua.org> Accessed 4/4/2004.
18. Dearnaley D, Kirby R, Kirk D, Malone P, Simpson R, Williams G. Diagnosis and management of early prostate cancer. Report of a British Association of Urological Surgeons Working Party. *BJU International* 1999;83:18-33.
19. Paris J, Ferranti J. The changing face of medicine: healthcare on the internet. *Journal of Perinatology* 2001;21:34-39.
20. Hardey M. Doctor in the House: The Internet as a Source of Lay Health Knowledge and the Challenge to Expertise. *Sociology of Health & Illness* 1999;21:820-835.
21. Anderson J, Rainey M, Eysenbach G. The impact of cyberhealthcare on the physician-patient relationship. *Journal of Medical Systems* 2003;27:67-83.
22. Hardey M. 'E-Health': The Internet and the Transformation of Patients into Consumers and Producers of Health Knowledge. *Information Communication & Society* 2001;4:388-405.
23. Kelly D. Male sexuality in theory and practice. *Nursing Clinics of North America* 2004;39(2):341-56.
24. Gray R, Fitch MI, Fergus K, Mykhalovskiy E, Church K. Hegemonic Masculinity and the Experience of Prostate Cancer: A Narrative Approach. *Journal of Aging & Identity* 2002;7:43-62.
25. Boehmer U, Clark J. Married couples' perspectives on prostate cancer diagnosis and treatment decision-making. *Psycho-Oncology* 2001;10:147-155.
26. Weinrich S, Reynolds W, Jr., Tinggen M, Starr C. Barriers to prostate cancer screening. *Cancer Nursing* 2000;23:117-21.
27. Pinnock C, O'Brien B, Marshall V. Older men's concerns about their urological helath: a qualitative study. *Australian and New Zealand Journal of Public Health* 1998;22:368-373.
28. McFall S, Ham R. Interpretation of prostate cancer screening events and outcomes: a focus group study. *Patient Education and Counselling* 2003;49:207-218.
29. Clarke-Tasker VA, Wade R. What we thought we knew: African American males' perceptions of prostate cancer and screening methods. *ABNF Journal* 2002;13(3):56-60.

30. O'Dell K, Volk R, Cass A, Spann S. Screening for prostate cancer with prostate-specific antigen test: Are patients making informed decisions? *Journal of Family Practice* 1999;48:682-688.
31. Ziebland S, Chapple A, Dumelow C, Evans J, Prinjha S, Rozmovits L. How the internet affects patients' experience of cancer: a qualitative study. *BMJ* 2004;328:564-570.
32. Tudiver F, Brown JB, Medved W, Herbert C, Ritvo P, Guibert R, et al. Making decisions about cancer screening when the guidelines are unclear or conflicting. *Journal of Family Practice* 2001;50(8):682-7.
33. Rozmovits L, Ziebland S. What do patients with prostate or breast cancer want from an Internet site? A qualitative study of information needs. *Patient Education and Counselling* 2004;53:57-64.
34. Eysenbach G, Ryoung E, Diepgen T. Shopping around the internet today and tomorrow: towards the millennium of cybermedicine. *BMJ* 1999;319:1294-1298.
35. Eysenbach G. Consumer health informatics. *BMJ* 2000;320:1713-1716.
36. Smith C, Cha J, Puno F, Magee J, Bingham J, van Gorp M. Quality assurance processes for designing patient education websites. *CIN: Computers, Informatics, Nursing* 2002.
37. NUA. How many online?: http://www.nua.ie/surveys/how_many_online/index.html, 2003.
38. Wukovitz L. Using internet search engines and library catalogs to locate toxicology information. *Toxicology* 2001;157:121-139.
39. Madan A, Frantzides C, Pesce C. The quality of information about laparoscopic bariatric surgery on the Internet. *Surgical Endoscopy* 2003;17:685-687.
40. Diaz J, Griffith R, Ng J, Reinert S, Friedmann P, Moulton A. Patients' use of the Internet for medical information. *Journal of General Internal Medicine* 2002;17:180-5.
41. Gupte C, Hassan A, McDermott I, Thomas R. The internet - friend or foe? A questionnaire study of orthopaedic out-patients. *Annals of the Royal College of Surgeons of England* 2002;84:187-192.
42. Paulter S, Tan J, Dugas G, Pus N, Ferri M, Hardie W, et al. Use of the internet for self-education by patients with prostate cancer. *Urology* 2001;57:230-233.
43. Sigouin C, Jadad A. Awareness of sources of peer-reviewed research evidence on the internet. *JAMA* 2002;287:2867-2869.
44. Tatsumi H, Mitani H, Haruki Y, Ogushi Y. Internet medical usage in Japan: current situation and issues. *Journal of Medical Internet Research* 2001;3:e12.
45. Specker C, Richter J, Take A, Sangha O, Scheider M. Rheumanet - A novel internet-based rheumatology information network in Germany. *British Journal of Rheumatology* 1998;37:1015-1019.
46. Allen E, Burke J, Welch M, Rieseberg L. How reliable is science information on the web? *Nature* 1999;402:722.
47. Lissman T, Boehnlein J. Health information on the Internet. *Psychiatric Services* 2002;53:348.
48. Silberg W, Lundberg G, Musacchio R. Assessing, controlling, and assuring the quality of medical information on the internet. *JAMA* 1997;277:1244-1245.
49. Biermann J, Golladay G, Greenfield M, Baker L. Evaluation of cancer information on the internet. *Cancer* 1999;86:381-390.
50. Baujard O, Baujard V, Aurel S, Boyer C, Appel R. Trends in medical information retrieval on internet. *Computers in Biology and Medicine* 1998;28:589-601.
51. Baujard O, Baujard V, Aurel S, Boyer C, Appel R. A multi-agent softbot to retrieve medical information on Internet. *Medinfo* 1998;9:150-154.
52. Tay J, Ke S, Lun K. MediAgent: a WWW-based scalable and self-learning medical search engine. *Proceedings/AMIA Annual Symposium* 1998:597-601.
53. Johnson D. Some benchmark searches for testing search capabilities and medical coverage of internet discovery tools. *Journal of Medical Internet Research* 2000;2:e19.
54. Joubert M, Aymard S, Fieschi D, Fieschi M. Quality criteria and access characteristics of web sites: proposal for the design of a health internet directory. *Proceedings/AMIA Annual Symposium* 1999:824-848.
55. Sacchetti P, Zvara P, Plante M. The internet and patient education - resources and their reliability: Focus on a select urologic topic. *Urology* 1999;53:1117-1120.
56. Wilson P. How to find the good and avoid the bad or ugly: a short guide to tools for rating quality of health information on the internet. *BMJ* 2002;324:598-602.

57. Ilic D, Bessell T, Silagy C, Green S. Specialised medical search engines are no better than general engines in sourcing consumer information about androgen deficiency. *Human Reproduction* 2003;18:557-561.
58. Hellawell G, Turner K, Le Monnier K, Brewster S. Urology and the internet: an evaluation of internet use by urology patients and of information available on urological topics. *BJU International* 2000;86:191-194.
59. Silverman D. *Qualitative Research: Theory, method and practices*. London: SAGE Publications, 2004.
60. Morgan D. *Focus groups as qualitative research*. California: Sage Publications, 1999.
61. Patton M. *Qualitative Research and Evaluation Methods*. Thousand Oaks, California: SAGE Publications, 2002.
62. Rice P, Ezzy D. *Qualitative Research Methods*. South Melbourne: Oxford University Press, 1999.
63. Charnock D, Shepperd S, Needham G, Gann R. DISCERN: an instrument for judging the quality of written consumer health information on treatment choices. *Journal of Epidemiology and Community Health* 1999;53:105-111.
64. Charnock D, Shepperd S. DISCERN and its role in the future of consumer health information. *Health Libraries Review* 2000;17:56-8.
65. Charnock D. The DISCERN handbook. *Radcliffe Medical Press Ltd* 1998.
66. NHMRC. How to use the evidence: assessment and application of scientific evidence. Canberra: National Health and Medical Research Council, 2000.
67. Woolf S, Krist A, Johnson R, Stenborg P. Unwanted control: how patients in the primary care setting decide about screening for prostate cancer. *Patient Education and Counselling* 2005;56:116-124.
68. Frosch D, Kaplan R, Felitti V. A randomised controlled trial comparing internet and video to facilitate patient education for men considering the prostate specific antigen test. *Journal of General Internal Medicine* 2003;18:781-787.
69. Flood A, Wennberg J, Nease R, Fowler F, Ding J, Hynes L. The importance of patient preference in the decision to screen for prostate cancer. *Journal of General Internal Medicine* 1996;11:342-349.
70. Gattellari M, Ward J. Does evidence-based information about screening for prostate cancer enhance consumer decision-making? A randomised controlled trial. *Journal of Medical Screening* 2003;10:27-39.
71. Volk R, Cass A, Spann S. A randomized controlled trial of shared decision making for prostate cancer screening. *Archives of Family Medicine* 1999;8:333-340.
72. Lawrence S, Giles C. Searching the world wide web. *Science* 1998;280:98-100.
73. Lawrence S, Giles C. Accessibility of information on the web. *Nature* 1999;400:107-109.
74. Larkin M. What's amiss with web search engines? *Lancet* 1999;354:260.
75. Butler D. Souped-up search engines. *Nature* 2000;405:112-115.
76. Graber M, D'Alessandro D, D'Alessandro M, Bergus G, Levy B, Ostrem S. Usage analysis of a primary care medical resource on the internet. *Computers in Biology and Medicine* 1998;28:581-588.
77. Eysenbach G, Kohler C. How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests and in-depth interviews. *BMJ* 2002;324:573-577.
78. Burls A, Gold L, Clark W. Systematic review of randomised controlled trials of sildenafil (Viagra) in the treatment of male erectile dysfunction. *British Journal of General Practice* 2001;51:1004-1012.
79. Martin-Facklam M, Kostrzewa M, Schubert F, Gasse C, Haefeli W. Quality markers of drug information on the Internet: an evaluation of sites about St. John's wort. *American Journal of Medicine* 2002;113:740-745.

Appendices

Appendix A: Focus Group Information Sheet

(NPC Group)



**MONASH UNIVERSITY
MONASH INSTITUTE OF HEALTH SERVICES RESEARCH**

INFORMATION SHEET

Male Information Needs and Prostate Cancer Screening A Consumer Perspective

Background about the project

There has been a lot of discussion within the medical and general community about prostate cancer screening. This discussion has been around the lack of research about whether the benefits of diagnosing prostate cancer early outweigh possible harms. Because the decision to be screened for prostate cancer is not a clear one, it is important that men facing this decision can access good information. The aim of this research project is to improve our understanding of why men may, or may not, choose to be screened for prostate cancer and what information sources they use when making this decision.

Your participation

If you are male, aged 45 years and over and understand English, we invite you to participate in a discussion group. It will allow you to discuss what information needs you would require when considering screening for prostate cancer, i.e. where would you get your information from and how much of an influence would it make in your final decision. This discussion group will last approximately 1 hour and will be taped, to aid in the analysis of issues raised. The group may consist of up to 8 men and you may contribute to the discussion as much, or as little, as you like. Participation in this study is entirely voluntary and you are free to withdraw from the investigation at any point. If you decide to participate you will be reimbursed for any out of pocket expenses.

Benefits/Risks of Participation

The final outcomes of the discussion will aid in the development of a questionnaire, which will further investigate issues raised in the discussion group. We hope this will ultimately lead to improved information being available to men facing the decision about whether or not to be screened for prostate cancer.

Confidentiality

All the information obtained from discussion group will be confidential. No information that could lead to the identification of any individuals will be disclosed in any reports on the project or to any other party. A tape of the discussion group will be made and kept in a locked filing cabinet at the Monash Institute of Health Services Research.

Investigators

The project will be run by the Monash Institute of Health Services Research based at the Monash Medical Centre. The investigators for the project are Associate Professor Sally Green, Associate Professor Gail Risbridger and Dragan Ilic, who is doing this research project as part of a PhD.

Ethical guidelines

This project is being carried out according to the National Statement on Ethical Conduct in Research Involving Humans (June 1999) produced by the National Health and Medical Research Council of Australia with the approval of the Monash University Ethics Committee.

Concerns and further information

Should you have a concern regarding the conduct of this research or require further information about the project please contact Dragan Ilic via telephone on (03) 9594-7523 or dragan.ilic@med.monash.edu.au, or Sally Green via telephone on (03) 9594-7531 or sally.green@med.monash.edu.au.

Complaints

You can complain about the study if you don't like something about it. To complain about the study, you need to phone 9905 2052. You can then ask to speak to the secretary of the Human Ethics Committee and tell him or her that the number of the project is XXXX, then discuss your complaint. You could also write to the secretary. That person's address is:

The Secretary
The Standing Committee on Ethics in Research Involving Humans
PO Box No 3A
Monash University
Victoria 3800
Telephone (03) 9905 2052 Fax (03) 9905 1420
Email: SCERH@adm.monash.edu.au

Thank you

Dragan Ilic
Telephone (03) 9594-7523
dragan.ilic@med.monash.edu.au
www.med.monash.edu.au/healthservices

(PC Group)



**MONASH UNIVERSITY
MONASH INSTITUTE OF HEALTH SERVICES RESEARCH**

INFORMATION SHEET

**Male Information Needs and Prostate Cancer Screening
A Consumer Perspective**

Background about the project

There has been a lot of discussion within the medical and general community about prostate cancer screening. This discussion has been around the lack of research about whether the benefits of diagnosing prostate cancer early outweigh possible harms. Because the decision to be screened for prostate cancer is not a clear one, it is important that men facing this decision can access good information. The aim of this research project is to improve our understanding of why men may, or may not, choose to be screened for prostate cancer and what information sources they use when making this decision.

Your participation

If you are male, understand English and have been diagnosed with prostate cancer, we invite you to participate in a discussion group. It will allow you to discuss what information needs you would require when considering screening for prostate cancer, i.e. where would you get your information from and how much of an influence would it make in your final decision. This discussion group will last approximately 1 hour and will be taped, to aid in the analysis of issues raised. The group may consist of up to 8 men and you may contribute to the discussion as much, or as little, as you like. Participation in this study is entirely voluntary and you are free to withdraw from the investigation at any point. If you decide to participate you will be reimbursed for any out of pocket expenses.

Benefits/Risks of Participation

The final outcomes of the discussion will aid in the development of a questionnaire, which will further investigate issues raised in the discussion group. We hope this will ultimately lead to improved information being available to men facing the decision about whether or not to be screened for prostate cancer.

Confidentiality

All the information obtained from discussion group will be confidential. No information that could lead to the identification of any individuals will be disclosed in any reports on the project or to any other party. A tape of the discussion group will be made and kept in a locked filing cabinet at the Monash Institute of Health Services Research.

Investigators

The project will be run by the Monash Institute of Health Services Research based at the Monash Medical Centre. The investigators for the project are Associate Professor Sally Green, Associate Professor Gail Risbridger and Dragan Ilic, who is doing this research project as part of a PhD.

Ethical guidelines

This project is being carried out according to the National Statement on Ethical Conduct in Research Involving Humans (June 1999) produced by the National Health and Medical Research Council of Australia with the approval of the Monash University Ethics Committee.

Concerns and further information

Should you have a concern regarding the conduct of this research or require further information about the project please contact Dragan Ilic via telephone on (03) 9594-7523 or dragan.ilic@med.monash.edu.au, or Sally Green via telephone on (03) 9594-7531 or sally.green@med.monash.edu.au.

Complaints

You can complain about the study if you don't like something about it. To complain about the study, you need to phone 9905 2052. You can then ask to speak to the secretary of the Human Ethics Committee and tell him or her that the number of the project is XXXX, then discuss your complaint. You could also write to the secretary. That person's address is:

The Secretary
The Standing Committee on Ethics in Research Involving Humans
PO Box No 3A
Monash University
Victoria 3800
Telephone (03) 9905 2052 Fax (03) 9905 1420
Email: SCERH@adm.monash.edu.au

Thank you

Dragan Ilic
Telephone (03) 9594-7523
dragan.ilic@med.monash.edu.au
www.med.monash.edu.au/healthservices

Appendix B: Focus Group Consent Forms



**MONASH UNIVERSITY
MONASH INSTITUTE OF HEALTH SERVICES RESEARCH**

PARTICIPANT CONSENT FORM

**Male Information Needs and Prostate Cancer Screening
A Consumer Perspective**

I agree to take part in the above Monash University research project. I have read the Explanatory Statement, which I keep for my records and understand that agreeing to take part means that I am willing to:

- Participate in a discussion group asking me about my informational needs and attitudes towards prostate cancer screening.

I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party.

Name: (please print)

Signature Date.....

Appendix C: DISCERN Tool

SECTION 1. Is the publication reliable?

1. Are the aims clear?
2. Does it achieve its aims?
3. Is it relevant?
4. Is it clear what sources of information were used to compile the publication (other than the author or producer)?
5. Is it clear when the information used or reported in the publication was produced?
6. Is it balanced and unbiased?
7. Does it provide details of additional sources of support and information?
8. Does it refer to areas of uncertainty?

SECTION 2. How good is the quality of information on treatment choices?

N.B. The questions apply to the treatment (or treatments) described in the publication. Self-care is considered a form of treatment throughout this section.

9. Does it describe how each treatment works?
10. Does it describe the benefits of each treatment?
11. Does it describe the risks of each treatment?
12. Does it describe what would happen if no treatment is used?
13. Does it describe how the treatment choices affect overall quality of life?
14. Is it clear that there may be more than one possible treatment choice?
15. Does it provide support for shared decision-making?

SECTION 3. Overall Rating of the Publication

16. Based on the answers to all of the above questions, rate the overall quality of the publication as a source of information about treatment choices

EVALUATION SCALE

1 No	2	3 Partially	4	5 Yes
------	---	-------------	---	-------

Appendix D: Levels of Evidence

Level of Evidence	Evidence obtained from
I	A systematic review or meta-analysis of all relevant randomised controlled trials.
II	At least one properly designed randomised controlled trial.
III	Well designed, pseudo randomised controlled trials (alternate allocation or some other method). Comparative studies with concurrent controls and allocation not randomised (cohort studies), case control or interrupted time series with a control group.
IV	Comparative studies with historical control, two or more single arm studies, or interrupted time series without a parallel control group. Case series (either post test, or pre test and post test), opinions of respected authorities, descriptive studies, reports of expert (that is consensus) committees and case studies.

Appendix E: Audited Financial Statement