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MPC MAJOR RESEARCH PAPER

A CREDIBILITY ASSESSMENT OF ONLINE BREAST CANCER INFORMATION

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## ABSTRACT

The rapid expansion of the Internet and changes in the health market are giving rise to the emergence of web-based tools for seeking health information. As a result, the Web empowers consumers by allowing them to access important medical information that has traditionally been mediated through healthcare professionals. Along with this growing trend comes the challenge of establishing credibility in a digital environment saturated with health information. One way to begin addressing this challenge is to assess the projection of credibility of health information found online. The purpose of this paper is twofold. Firstly, to develop a better understanding of how projections of credibility might differ between traditional and non-traditional online health sources. The former defined as websites belonging to formal and conventional institutions and the latter defined as informal and unconventional organizations. Secondly, to develop some strategic approaches that might be employed to enhance perceptions of online credibility. This paper conducts a content analysis using the Health on the Net Foundation's Code of Conduct for medical and health websites and DISCERN, an instrument that assesses the quality of written information about treatment choices (DISCERN, 2012).

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## Introduction

The rise of the Internet as a powerful information source in conjunction with changes in the healthcare market, such as— the emergence of new digital technologies, changes in consumer behavior, movement away from clinical care toward patient-centered care and increased pressures to contain healthcare costs—have together given rise to the emergence of consumer digital health. Consumer digital health can be defined as “solutions and services that use digital communication technologies and are designed to meet the needs of consumers through health education, wellness and disease management” (Cameron, Jones, & Litinski, 2010, p.1). This new approach to healthcare shifts focus away from the healthcare provider and places the consumer at the center of his or her own care. Research in this area reveals that consumers are increasingly interested in web-based solutions designed to help them elevate and manage their healthcare (Tilley & Kaihoi, 2011, p.19). As a result, consumer digital health is meant to complement the patient-centered care movement, which received considerable attention after the publication of the 2001 Institute of Medicine report, *Crossing the Quality Chasm*, by addressing some of the core values for care that it defines. The 2001 study created a framework for improving quality of care that consists of six core values: patient care should be safe, effective, efficient, patient-centered, timely and equitable (Snyder, Wu, Miller, Jensen, Bantug & Wolff, 2011, p.211). According to the study, care that is patient-centered is collaborative and includes the patient in clinical decision-making and in the monitoring of his or her own health (Snyder, Wu, Miller, Jensen, Bantug & Wolff, 2011, p.212). By delivering digital tools that put the patient at the center of care and facilitate personal health engagement, consumer digital health seeks to address some of these values. It seeks to leverage digital and personalized healthcare tools to



reach beyond the doctor's office and provide information sources outside of the context of the traditional clinic.

With the rapid expansion of the Internet, it is critical to better understand what kinds of health information consumers receive and how they receive it. According to a 2006 Pew Internet & American Life Project survey, 58% of Internet users changed how they treated an illness or condition based on the information they found online. Moreover, 55% of respondents said that online information changed how they approached the maintenance of their health or the health of someone else. 54% said that the information they found online led them to ask more questions during doctor's visits or seek a second opinion from another doctor (Ledford, 2009, p.59). These findings suggest that the health information that individuals find online has an effect on their overall health care. In Canada, studies show that searching for medical or health-related information is the third most popular form of Internet use after email and general browsing (Schiavo, 2008, p.10). Since the definition of "health" is wide-ranging the popularity of seeking health information online may exceed what survey research suggests. For example, Lenhart et al. (2005) found that when adult Internet users were asked, "if they ever go online to simply look for 'health or medical information'...66% report doing so." However, "when [asked] about a wide range of health topics (e.g., 'Have you ever looked online for information about exercise or fitness? Or 'For information about immunizations or vaccinations?') 80% of adult Internet users [said that] they have researched at least one of those specific health topics at some point" (Lenhart, Madden, & Hitlin, 2005, p.42).

If changes in the healthcare market are giving rise to the usage of web-based technologies for health information seeking, then establishing credibility may be among the biggest challenges that web-based consumer digital health solutions will face, particularly in a market that is already

saturated with health information. Conventionally, healthcare providers have been reluctant to embrace IT tools for health education and have preferred to act as intermediaries of health information, since the accuracy of online health information can vary (Ledford, 2009, p.67). However, if more consumers are seeking health information online, then the health system will need to find ways to address the added challenge of false information potentially leading consumers away from proper care (Eastin, 2001). One way to begin addressing this challenge is to assess the projection of credibility of health information found online.

This research study seeks to provide a preliminary analysis of traditional and non-traditional online health sources, specifically on breast cancer information, in order to identify a strategic approach that may be employed to enhance the credibility of online health sources. Traditional online health sources are defined as websites belonging to formal and conventional institutions, such as: hospitals, national institutions, universities and government agencies. Non-traditional online health sources are defined as informal and unconventional organizations, such as not-for-profits, voluntary health organizations, blogs and support groups. It is hoped that analyses of traditional and non-traditional online health sources will highlight areas where these sources will need to improve in order to compete with emerging consumer digital health tools. Therefore, this study will seek to answer the following research questions:

- With the emergence of consumer digital health, how might projections of credibility vary between traditional and non-traditional online health sources?
- How do traditional and non-traditional online health sources encourage credibility?
- How can consumers assess content quality?
- And how can the credibility of online health sources be enhanced?

## Theoretical Framework

Of Aristotle's three proofs —logos, pathos and ethos —ethos is the classical presentation of credibility. According to Aristotle, ethos refers to the perceived credibility of a source in the minds of receivers. Aristotle considers ethos to be the most potent means of persuasion (Cooper, 1932) because receivers are thought to be more likely to accept a weak argument from a credible source than a strong argument from a less credible source. Credibility is therefore infinitely connected to persuasion and more influential than logic. Aristotle conceives of ethos as made up of three dimensions: intelligence, character and good will. It is argued that if the audience believes that the source has intelligence, character and good will, the audience will be more inclined to trust the sender's judgments. Aristotle argues that credibility can be communicated through the tone and style of a message as well as through the reputation of the sender. For example, in the opening of Plato's *Phaedrus*, the Greeks use family reputation to establish a sense of ethos. Ethos, in this scene, relies on already established and earned titles, which in contemporary times may equate to a source's perceived expertise or authority on a subject. Ethos, as Aristotle views it, gives a sender the authority to persuade others, but the receiver who makes up their own mind about the sender's trustworthiness determines credibility (Kallendorf, & Kallendorf, 1985, p.36). Therefore, the audience bestows credibility upon the sender when the sender is successful in evoking an image of ethos. This early discussion of ethos demonstrates the influence of persuasion on an audience's trust and behavior.

Hovland and Weiss' 1951 landmark study on credibility demonstrates how an audience's perception of a source's credibility can influence communication effectiveness. It is argued that an audience is more likely to trust a source that they perceive as credible than a source that they perceive as less credible. Their study specifically looks at the effects of predisposition on

consumer perceptions of credibility and highlights key areas to consider when persuading consumers to accept the credibility of non-traditional sources of information. Their findings suggest that predisposition leads to justification and therefore in order to establish credibility, sources of information must focus on producing a perception of expertise in order to establish a sense of trustworthiness. In their study, Hovland and Weiss (1951) found that participants who were predisposed to a particular opinion felt 'justified' over 70% of the time (Robins, Holmes, & Stansbury, 2010, p.14). Building upon the earlier source-message-channel-receiver model of communication and theories of persuasion and social judgment, their study has important implications for technology adoption, and in particular for user acceptance of the credibility of non-traditional information sources.

Blumler and Katz's (1974) uses and gratification theory provides insight into what motivates specific medium use. Blumer and Katz (1974) suggest that consumers seek out those sources that best fulfill their individual needs. A key assumption of this theory is that consumers have a number of communication media available to them so their perceptions play a primary role in their medium use. It is argued that different media offer different opportunities for gratification and therefore the more fulfilling a medium the more likely a consumer is to choose that medium over others (Blumler, & Katz, 1974). In terms of health information seeking, the Internet allows consumers to choose between both traditional and non-traditional online sources of health information. As a result, the gratification opportunities inherent in each may influence consumer perceptions and play a role in determining which medium consumers ultimately choose as well as the credibility and reliability of the health information they receive.

Wilson's 1983 theory of cognitive authority suggests that sources that project an image of credibility receive the greatest recognition from individuals. Wilson (1983) writes that "our

cognitive authorities are clearly among those we think credible sources” (Wilson, 1983, p.16).

Key to Wilson’s theory is the notion that individuals determine credibility in two ways: from first-hand experience or from what others have told them. In this way, cognitive authorities are constructed based on an individual’s perception of their own experience and the experience of others. Though individuals are limited in their ability to determine credibility by their first and second-hand understanding, Wilson (1983) argues that perception of a source’s trustworthiness plays a key role in determining which sources become “cognitive authorities”. Those sources deemed to be cognitive authorities are said to differ from other sources with ascribed authority or ascribed power because not only are cognitive authorities considered competent but they also influence the individual’s thoughts and opinions. Consistent with other research on credibility, Wilson (1983) maintains that cognitive authority or ‘credibility’ is assigned to sources based on what individuals consciously recognize as credible.

## Review of Literature

There is currently a large body of research on the topic of online information seeking. For instance, Anderson (2004) explores the demographic characteristics of consumers that use the Web to acquire medical information. His study suggests that those who are older, more educated and have higher household incomes are more likely to venture online for medical information. Additionally, his study identifies the following key barriers to Internet use for health-related purposes: potential threats to privacy, inaccuracy of information, problems in evaluating the quality of information and services obtained from the Web, and physician disapproval. The barriers identified by Anderson highlight key obstacles that may affect the ability of both traditional and non-traditional online health sources to disseminate health information to consumers (Anderson, 2004).

Brashers, Goldsmith and Hsieh (2002) note that information can be manipulated to confirm or disconfirm the health beliefs of consumers. They argue that some information management activities are more adaptive than others because they depend on the goals of consumers and on cross-cultural understanding of different information sources. Therefore, they suggest that interpreters of information play a role in the effectiveness of exchanges of information. They put forward ways in which information seekers might manage conflicting and sometimes overwhelming health information, particularly when information is being communicated through multiple information channels (Brashers, Goldsmith, & Hsieh, 2002).

Cline and Haynes (2001) list some key advantages to seeking health information online, some of which include: widespread access, anonymity, potential for interactivity, social support and the ability to tailor information to one's needs. They argue that the health industry should be concerned with the credibility of online health information because it influences health beliefs

and behaviors, healthcare, medical outcomes, and ultimately the healthcare system. Moreover, the authors discuss some of the challenges related to obtaining health information online, such as: inequitable distribution, design and navigability. They propose that given changes in health communication there is a growing need to enforce quality standards and criteria for evaluating health information found online. Furthermore, they suggest some ways in which the health system might begin to fill the 'net-gap' of information quality found online (Cline & Haynes, 2001).

Goldsmith (2001) argues that access to information is essential in order to continuously assess, maintain or change the health and health behaviors of consumers. Consequently, she argues that research must shift away from “measuring levels of uncertainty towards measuring conflicting meanings of uncertainty” (Goldsmith, 2001, p.514). By doing this, she acknowledges that consumer behaviors have changed and so research must also change to reflect the communication practices in which consumers currently engage. Rather than focusing on predicting consumer behaviors, such as whether or not consumers will seek information online, she proposes a shift in focus towards the examination of why consumers choose specific media.

Johnson and Meischke (1992), examine the role that traditional sources play in accessing health-related information online. Their study assessed three dimensions in order to determine which communication channels respondents preferred to receive cancer-related information, including: editorial tone (credibility), communication potential (presentation and style) and utility. Their statistical analyses revealed that traditional sources of health information were considered by respondents to be more credible than non-traditional sources regardless of whether or not respondents perceived the information communicated by traditional sources to be more

understandable (Johnson & Meischke, 1992). This finding suggests that positive perceptions of credibility are related to consumer usage of particular communications channels.

Finally, Johnson's (1997) comprehensive model of information-seeking is useful in explaining consumer health information-seeking behaviors. In his model, Johnson (1997) identifies different factors that motivate consumers to choose a particular channel for health information seeking. Although Johnson's model specifically looks at cancer information, it is applicable to health information in general and is therefore a useful tool in assessing the credibility of online health information. Additionally, Johnson's model incorporates uses and gratification research while emphasizing the determining characteristics of different channels. Essentially, Johnson (1997) considers how consumer perceptions of other information sources might shape information-seeking behavior (Johnson, 1997). Johnson's model is valuable to the present study because it takes into account the complexities involved in choosing information sources that affect consumer health.



## Methods

The present study reviewed the fact pages on breast cancer information of a subsample of four traditional and non-traditional online health sources. Two traditional and two non-traditional online health sources were chosen based on Google's ranking of the most popular online health sources of breast cancer information. The websites selected for this study each contained comparable fact pages on the topic of breast cancer. To ensure that a range of sites were represented, the websites comprised one of each of the following website genres:

### Traditional online health sources:

CIBC Breast Centre at St. Michael's Hospital—*Hospital*

Breast Cancer: Public Health Agency Canada—*Government agency*

### Non-traditional online health sources:

The Susan G. Komen Breast Cancer Foundation—*Not-for-profit*

Breast Cancer at About.com—*Blog*

## Content analysis

To determine each online health source's projected credibility and effectiveness, a content analysis was conducted using two separate units of analysis. These included: Health on the Net Foundation's Code of Conduct for medical and health websites and DISCERN, an instrument designed "to judge the quality of written information about treatment choices" (DISCERN, 2012). Health on the Net is an independent foundation based in Geneva and was founded with the goal of "promoting the effective and reliable use of the new technologies for

telemedicine around the world” (Health on the Net Foundation, 2011). Its code of conduct (HONcode) ensures that web-based medical information is trustworthy and is made up of the following eight principles:

The HON principles:

1. Authoritative
2. Complementarity
3. Privacy
4. Attribution
5. Justifiability
6. Transparency
7. Financial disclosure
8. Advertising policy

\* A definition of each principle is available in *Appendix A*.

Using the HONcode as a unit of analysis, the preliminary content analysis examined each online health source’s front page to evaluate compliance with the HONcode and its principles. The front page was purposely chosen because it is the page that often establishes credibility and serves as the gateway to more detailed health information. According to a study conducted by Qiu, Liu, and Cho (2005), 45% of information seekers move on to another website after visiting only the first page, and the first page often determines how ‘deep’ the user will go into the webpage, for example, whether or not the user will visit linked information (Ledford, 2009, p.61). The preliminary content analysis was based on the texts of each medium, which were defined as any form of communicative language. The level of compliance of each webpage with

the HONCode and its principles defined the credibility of each online health source. Webpages with the greatest compliance were considered more credible and webpages with the lowest compliance were considered less credible.

As a rating tool, DISCERN was used to conduct a secondary content analysis based on the texts, as previously defined, of the same online health sources. This secondary analysis compared the findings based on DISCERN against the findings of the preliminary content analysis based on HONcode. Widely used as an analytical tool to measure the quality of written health information, DISCERN has been used as an analytical tool in the following studies: Charnock et al. (1999), Rees et al. (2002), Shepperd et al. (2002), and Khazaaal et.al (2009). The DISCERN rating tool consists of a questionnaire of 15 questions, each representing a separate quality criterion, and is organized in the following three sections:

- **Section 1** (Questions 1-8) Addresses issues of reliability and assesses the trustworthiness of the information source.
- **Section 2** (Questions 9-15) Focuses on information describing treatment choice or choices, including no treatment and alternative options for care.
- **Section 3** (Question 16) Is based on the answers to questions 1-15 and provides the overall quality rating of the information source.

Each question is rated on a five-point scale that ranges from No to Yes. The overall rating depends on whether the consumer considers the quality criterion in question to be present or fulfilled by the information source. An answer of five indicates complete fulfillment with the quality criterion, an answer between two and four indicates partial fulfillment of the quality

criterion and an answer of one indicates that the information source did not fulfill the quality criterion (DISCERN, 2012). An example of the DISCERN instrument can be found in *Appendix A*.

An analysis of breast cancer information was purposely chosen as a result of the wide range of information sources on breast cancer available on the Web. Studies show that the majority of online health information seekers are women, and assuming that the target audience is female, information targeted towards women may draw more inferences from a health communications perspective. In one study, 85% of women stated that they use websites to access health-related information and frequently research information related to women's health online (Ledford, 2009, p.58). Online health information targeted towards this particular group could provide added insight into how effective each online health source is in disseminating health-specific information.

## Analyses

### Content analysis: Traditional online health sources

#### **CIBC Breast Centre at St. Michael's Hospital**

A preliminary content analysis of the front page of the CIBC Breast Centre at St. Michael's Hospital website was conducted using the HONcode. The CIBC Breast Centre makes up one portion of the St. Michael's Hospital website and can be accessed from the homepage as follows: Patient Care>Patient & Family learning Centre>Patient Care A to Z>B>Breast Centre>CIBC Breast Centre. The following analysis provides a brief overview of which principles of the Health on the Net Foundation's Code of Conduct were met or not met by the CIBC Breast Centre.

Clearly stating on the front page the name and position of the Medical Director, CIBC Breast Centre, met the principle of authority. This information was located under the heading "Director's Message" and included a personal note from the Director along with a photograph. The personal note discussed a particular research area that the Director had pioneered as well as an overview of the Director's involvement in the organization. On the front page, the Director was referred to as Dr., the abbreviation of Doctor, although no additional information regarding the Director's education or areas of specialization was provided. Still, a sense of authority was established through stating the Director's occupation, purpose and association with St. Michael's Hospital.

The CIBC Breast Centre met the principle of complementarity by providing supplementary traditional and non-traditional breast cancer information. For example, on the front page under the heading "Care and Treatment" the website directed users toward additional services provided by certified nurses and mammography specialists. The website provided links

under the same heading to the diagnostic clinic, an offline traditional health source, as well as links under the heading “Education” to a variety of online and offline traditional and non-traditional sources of health information. Therefore, supplementary information was included to complement but not replace traditional sources of breast cancer information.

The CIBC Breast Center met the principle of privacy by presenting a stated privacy policy. The privacy policy was located at the bottom of the front page and was hyperlinked via the heading “Website Privacy.” This link directed users to a statement of commitment to protecting the privacy of website visitors. Within this statement, the website offered its guarantee that the handling of all personal information by the hospital would be governed by the *Freedom of Information and Protection of Privacy Act* (FIPPA), which it linked to. Additionally, it stated that all personal information would be kept confidential and would be secured through the *Personal Health Information Protection Act* (PHIPA), which it also linked to. A link to St. Michael’s Hospital’s Information Practices Statement was presented and the contact information for the Hospital’s Information Access and Privacy Office was made available. While this information could have been displayed more prominently as opposed to linked to at the bottom of the front page, it satisfied the privacy principle as defined by HON.

The attribution principle was noticeably unmet. Sources of medical information were not cited and there were no dates to provide information about their timeliness. Although a copyright year was provided at the bottom of the front page, the copyright did not refer to the sources but to the page itself, which did not indicate how up-to-date the information might be. Additionally, links to other resources led to groups and associations as opposed to sources of information. Therefore, all of the information on breast cancer presented by the CIBC Breast Centre relied on its association with St. Michael’s Hospital as opposed to the literature on breast cancer. In this

way, the website lead visitors away from online sources of information by focusing on the hospital as a treatment centre.

The principle of justifiability was met since some justification was given for the majority of the claims made by the CIBC Breast Centre. For example, under the heading “Breast Screening” the CIBC Breast Centre acknowledged its affiliation with the Ontario Breast Screening Program (OBSP) and provided a link to the OBSP to corroborate its own guide for breast screening and establish authority. Clear reasoning was given for each treatment choice and in many cases justification was provided for why one treatment option might be more suitable than another. For example, the CIBC Breast Centre’s description of the Surgical Treatment of Ductal Carcinoma in Situ (DCIS) states: “Breast conservation therapy is thought to be as effective as mastectomy surgeries for women with early stages of breast cancer. However, breast conservation techniques may not be possible for women with more advanced stages of breast cancer” (St. Michael's Hospital, 2012).

The principle of transparency was met, as contact information for the CIBC Breast Centre was clearly marked on both the right side and bottom of the front page. On the right side of the front page contact details were marked both visually and textually under the heading, “Contact Us”. Contact information included: the phone number, fax number, address and directions for the CIBC Breast Centre. A variety of social media sites were linked to above the “Contact Us” heading and these included links to an RSS feed, Twitter, Facebook, YouTube and LinkedIn. At the bottom of the front page, the website encouraged users to “follow” the CIBC Breast Centre through the various social media sites it listed.

The principle of financial disclosure was not met by the CIBC Breast Centre. No information was provided for whether the CIBC Breast Centre had received any financial

support or donations. Therefore, users could not be certain that financial interests or relationships did not affect the objectivity of the content presented by the CIBC Breast Centre. Unlike the American public-private health care system, in Canada, most treatment is covered through the health care system. If the Centre bears the name of CIBC, the assumption is that the bank has paid a sum to sponsor or fund the website. Since the information presented could potentially impact the decision making of users, it would be sensible to provide some form of financial disclosure.

The advertising principle was not met by the CIBC Breast Centre because no distinction was made between advertising and editorial content. If there were advertisements on the front page or in subsequent pages they were not clearly marked as such, although the name of the Centre itself could be interpreted as an advertisement for CIBC. Still, no information was provided to guide users in distinguishing content by the CIBC Breast Centre from possible content by third-parties.

Using the DISCERN tool, a second content analysis was conducted on the CIBC Breast Centre webpage. The following analysis summarizes key findings from each section of the DISCERN tool. A complete analysis of the CIBC Breast Centre webpage can be found in *Appendix B*.

## Section 1: (Questions 1-8)

The first question (“Are the aims clear?”) was given a rating of four indicating that the aims of the CIBC Breast Centre were clear but somewhat incomplete. A rating of four was given because although the front page defined the purpose of the CIBC Breast Centre and its focus, it did not explicitly state its central aim. Still, a high rating of four was given because the CIBC



Breast Centre outlined its commitments and goals under the heading “Director’s Message”. The Director’s Message stated: “[We] are committed both to training the next generation of health care providers and to discovering answers to important questions about breast cancer diagnosis and treatment” (St. Michael's Hospital, 2012). Therefore, the aims of the CIBC Breast Centre were mostly clear.

The second question (“Does it achieve its aims?”) was given a rating of three indicating that some but not all of the content presented achieved the CIBC Breast Centre’s aim. A rating of three was given because on the front page and in subsequent pages the CIBC Breast Centre website delivered only some of the commitments and goals it outlined on the front page and in the ‘Director’s Message’. For instance, it answered questions regarding the diagnosis and treatment of breast cancer but did not demonstrate how the CIBC Breast Centre might ‘discover’ answers to important questions. Likewise, it provided some information on training health care providers but did not demonstrate how it planned to achieve or currently achieves this aim.

The third question (“Is it relevant?”) was given a rating of five indicating that all of the information provided on the front page and in subsequent pages was relevant to the CIBC Breast Centre’s stated commitments and goals. A rating of five was given because all of the content related to breast cancer, the CIBC Breast Centre, the treatment of breast cancer or its diagnosis. For example, the linked headings located on the front page included: Clinics, Care and Treatment, Education and Hours (of operation), all of which were relevant to the CIBC Breast Centre.

The seventh question (“Does it provide details of additional sources of support and information?”) was given a rating of five indicating that the publication provided full details of additional sources of support and information apart from sources from the organization itself. For

example under the heading “Education” located on the front page was a subheading titled “Resources” that included links to breast cancer information. These were divided into the following three categories: Breast Cancer Information, Other, and Information Booklets You Can Find Online. Under “Breast Cancer Information,” the CIBC Breast Centre linked to a variety of support sources including a support group, national network and university page. Under the category “Other,” the CIBC Breast Centre provided links to alternative sources of support, such as Gilda’s Club –Toronto, a support and networking group. Under the category “Online Booklets You Can Find Online” the CIBC Breast Centre provided booklets developed by the Canadian Cancer Society and the Canadian Breast Cancer Foundation. Therefore, a rating of five was given because an assortment of additional sources of support and information was provided.

## Section 2: (Questions 9-15)

The ninth question (“Does it describe how each treatment works?”) was given a rating of five indicating that each treatment included a description of how the treatment works. For example, the CIBC Breast Centre described the procedure of a breast ultrasound from the moment the gel is applied to the way in which a special instrument called a transducer would be moved across the breast. It is worth noting that although each treatment is described, the focus of each description is technical and does not include social or emotional elements. Still, a rating of five was given because each treatment was accompanied by some description of how it works.

The 10<sup>th</sup> question (“Does it describe the benefits of each treatment?”) was given a rating of one indicating that no benefits were described for any of the treatments listed. Instead, each treatment included a step-by-step description of how the treatment works. In some instances descriptions of treatments were accompanied by an explanation of why one treatment might be

superior to another. However, no benefits to the patient were described. Therefore, a low rating of one was given because the descriptions did not include the benefits of each treatment.

The 11<sup>th</sup> question (“Does it describe the risks of each treatment?”) was given a rating of two indicating that risks were described for some but not all of the treatments listed. For example, out of nine surgical oncology treatments, only one described a risk associated with a particular treatment choice. In the CIBC Breast Centre’s description of Axillary Dissection, it cautions that “lymphedema can also develop, in four to five per cent of women, after having an axillary node dissection...As a result, lymphedema can cause your body to hold onto fluid causing your arm or hand to swell” (St. Michael's Hospital, 2012). Therefore, a low rating of two was given because the risks of each treatment were only described in one out of nine treatments.

The 12<sup>th</sup> question (“Does it describe what would happen if no treatment is used?”) was given a rating of one indicating that the publication did not include any reference to the risks or benefits if no treatment were used. The content was written with the assumption that the patient would choose one of the treatment options listed. Therefore, there was no information on the effects of not choosing a particular treatment option. Moreover, no support or additional information was provided to complement the no-treatment option.

The 13<sup>th</sup> question (“Does it describe how the treatment choices affect overall quality of life?”) was given a rating of one indicating that there was no mention of overall quality of life in relation to treatment choices. Quality of life was not mentioned in any of the treatments or in any of the texts. Therefore, a low rating of one was given because quality of life was not included as part of the discourse on treatment.

The 14<sup>th</sup> question (“Is it clear that there may be more than one possible treatment choice?”) was given a rating of five indicating that the publication made it clear that there might

be more than one possible treatment choice. For example, the CIBC Breast Centre listed seven diagnostic services and nine forms of surgical oncology. Therefore, a high rating of five was given because the CIBC Breast Centre made it clear that there may be more than one possible treatment choice.

The 16<sup>th</sup> question produced a rating of one indicating that the publication is poor quality. A rating of one was given because eight questions rated high—four or above—while six questions rated low—two or below.

### **Breast Cancer: Public Health Agency of Canada**

The Public Health Agency of Canada (PHAC) is responsible for public health in Canada. A fact page on breast cancer can be found on the PHAC website under information about diseases and conditions. This information includes issues concerning breast cancer and consists of one full page with links to further information. From the front page, the fact page on breast cancer can be accessed as follows: Home>Chronic Diseases>Cancer>Breast Cancer.

According to the definition provided by HON, PHAC did not meet the principle of authority. No qualifications were provided for the author(s) of the content on either the home page or in subsequent pages. Under the heading “About the Agency” no information was communicated in regards to where the information presented on breast cancer originated. As a result, no sense of authority was established by PHAC.

The principle of complementarity was met by PHAC because supplemental information was provided to support but not replace traditional sources of health information, including information from the agency itself. Under the heading “Knowledge Development and Exchange” located on the front page was a list of breast cancer publications, breast cancer

clinical practice guidelines, Canadian best practices and information on chronic diseases and injuries in Canada. In addition to these sources of information, under the heading “Links” located on the front page was a list of links on breast cancer from both traditional and non-traditional online health sources.

The principle of privacy was not met by PHAC because no statement of privacy practices was present on its website. Under the heading “Transparency” located on the front page was a subheading titled “Completed Access to Information Requests” and under this heading was a link to “Access to Information and Privacy”. Within this section, there was a brief statement titled “Privacy”, however this information pertained to the Government of Canada and its *Privacy Act*, and did not include information regarding PHAC. Therefore, the principle of privacy was not met because the information provided on privacy was not related to the website or its users.

The attribution principle was not met by PHAC because there were no dates or citations provided for sources of medical information. A last modified date was included at the bottom of the front page but it was not clear what information had been modified or how up-to-date specific information might be. Where studies or specific statistics were mentioned, no information was provided on where the information had been derived. Therefore, the attribution principle was not met because there were no specific dates or citations provided for sources of medical information.

The principle of justifiability was not met by PHAC because no justification was provided for claims made about specific treatment choices. Three treatments were measured under the heading “How is Cancer Treated?” but no reasoning was provided to support claims made by PHAC. Similarly, no information was introduced to bolster the validity of the claims or

demonstrate PHAC's objectivity.

The principle of transparency was met by PHAC because contact details were provided under the heading "Contact Us," which was located at the top of the front page. Under this heading the mailing addresses and email addresses of PHAC were provided as well as the mailing addresses and telephone numbers of regional offices. A general enquiries field was also included where users could enter their name and email address to submit their comments to PHAC.

The principle of financial disclosure was met by PHAC because information regarding funding was made available to users. Under the heading "Transparency" located on the front page was a subheading titled "Proactive Disclosure," which disclosed expenses, contracts, position reclassification and grant and contribution awards over \$25,000. Although details of financial support were limited to contributions in excess of \$25,000, providing information on funding met the principle of financial disclosure as defined by HON.

PHAC did not meet the principle of advertising because it did not distinguish advertising content from editorial content. Although PHAC provided a disclosure of contracts, no specific information on advertising was made available to users.

## Section 1: (Questions 1-8)

Using the DISCERN tool, a second content analysis was conducted on the PHAC fact page on breast cancer. The first question ("Are the aims clear?") was given a rating of five indicating that PHAC presented clear aims. A rating of five was given because PHAC clearly presented its mission, vision and values under the heading "About the Agency" located on the front page. Under this heading PHAC described its mandate, background and organizational

aims. Under the heading “Initiatives, Strategies, Systems and Programs” located on the bottom of the front page was a detailed description of the initiatives that PHAC supports.

The second question (“Does it achieve its aims?”) was given a rating of three indicating that only some of PHAC’s aims were achieved. A rating of three was given because the aims that PHAC described were broad and included aims such as: to promote health and to prepare and respond to public health emergencies. Though PHAC promoted health through the texts on its website, it did not demonstrate how it prepares or responds to public health emergencies. Therefore a rating of three was given because it partially achieved the aims that it listed.

The third question (“Is it relevant?”) was given a rating of five indicating that all of the information provided was relevant to the aims of PHAC. A rating of five was given because information related to breast cancer and promoting public health. The front page consisted of: a description of breast cancer, risk factors, ways to manage breast cancer, facts and figures, knowledge development and exchange, initiatives, strategies, systems and programs and links to further information on breast cancer. Therefore, a high rating of five was given because all of the information provided related to breast cancer and the promotion of public health.

The seventh question (“Does it provide details of additional sources of support and information?”) was given a rating of five indicating that PHAC provided additional sources of support and information apart from sources provided by the website itself. Under the heading “Breast Cancer Links” located at the bottom of the front page, 15 additional sources of breast cancer information were provided. These included traditional sources of health information, such as the national institute of health and non-traditional sources of health information, such as Willow Breast Cancer Support Canada, a national support group. International sources, such as the International Agency for Research on Cancer and Cancer Research UK were also included.

Therefore, a rating of five was given because additional sources of support and information were provided by PHAC.

## Section 2: (Questions 9-15)

The ninth question (“Does it describe how each treatment works?”) was given a rating of three indicating that descriptions of how each treatment works were incomplete. PHAC presented surgery, chemotherapy and radiation therapy as viable treatment options, however none was wholly described. For example, the description for surgery stated, “Surgery – removes part, or all, of the tumor” (Public Health Agency of Canada, 2012). This description did not distinguish the type of surgery, the type of tumor or how the tumor would be removed. Similar descriptions were provided for chemotherapy and radiation therapy. Therefore, a rating of three was given because although PHAC described how each treatment works, descriptions were incomplete and missing important information.

The 10<sup>th</sup> question (“Does it describe the benefits of each treatment?”) was given a rating of two indicating that benefits were described for some but not all of the treatments listed. Of the three treatments described, only one explained benefits. The description of chemotherapy included an explanation of how chemotherapy might help stop cancer cells from multiplying. A low rating of two was given because two of three treatments listed did not include any description of potential benefits.

The 11<sup>th</sup> question (“Does it describe the risks of each treatment?”) was given a rating of one indicating that no risks were described for any of the treatments listed. The three treatments included brief or incomplete descriptions of the treatments but none mentioned any form of risk. Therefore, the lowest rating was given because risks were not included in any of the texts.



The 12<sup>th</sup> question (“Does it describe what would happen if no treatment is used?”) was given a rating of one indicating that PHAC did not describe what would happen if no treatment was used for any of the treatments listed. As previously mentioned the descriptions of each treatment were brief or incomplete and assumed that the user would engage in some form of treatment. Therefore a low rating of one was given because there was no mention of a ‘no treatment’ option.

The 13<sup>th</sup> question (“Does it describe how the treatment choices affect overall quality of life?”) was given a rating of one indicating that there was no description of how treatment choices might affect overall quality of life. Treatments were described concisely and technically and therefore a low rating of one was given because quality of life was not included in any of the descriptions of treatment.

The 14<sup>th</sup> question (“Is it clear that there may be more than one possible treatment choice?”) was given a rating of five indicating that the publication made it clear that there may be more than one possible treatment choice. PHAC mentioned three distinct treatment choices that could be used to treat breast cancer. Therefore, it was evident that there could be more than one treatment choice.

The 16<sup>th</sup> question produced a rating of one indicating that the publication is poor quality. A rating of one was given because five questions rated high—four or above—while seven questions rated low—two or below.

## Content analysis: Non-traditional online health sources

### The Susan G. Komen Breast Cancer Foundation

The Susan G. Komen Breast Cancer Foundation is a self-proclaimed global thought

leader on breast cancer and the world's largest grassroots organization of breast cancer survivors and supporters. Information on breast cancer can be accessed from the homepage as follows:

Home> Understanding Breast Cancer.

The Susan G. Komen Breast Cancer Foundation met the authoritative principle because the qualifications of its author(s) were stated. Though the website did not list one particular content author, where informative content was present the author's details were provided. Full descriptions of members of the Scientific Advisory Board (SAB) were included along with the educational and professional backgrounds of board members. Therefore, the authoritative principle was met because informative content was accompanied by some indication of the author(s) qualifications.

The Susan G. Komen Breast Cancer Foundation met the principle of complementarity by providing information that supported but did not replace information from traditional health sources. Under the heading "Komen Videos" located on the right-hand navigation bar were links to informational videos featuring medical professionals and hospitals. Under the heading "Support" located on the left-hand navigation bar were links to non-traditional sources of breast cancer information, such as support groups and spiritual advisors. Links to traditional health sources, such as healthcare providers, were also included. The left-hand navigation bar contained a heading titled "Questions to ask your doctor," which prompted users to engage in a dialogue with their healthcare provider. Under the heading "Resources" located on the left-hand navigation bar were several links to other websites on breast cancer. Therefore, the principle of complementarity was met because the website made reference to both traditional and non-traditional sources of breast cancer information.

The Susan G. Komen Breast Cancer Foundation met the principle of privacy by clearly

stating its privacy policy via a link situated at the bottom of the front page. Under the heading “Privacy Policy,” it outlined its commitment to responsible information handling practices. It provided a summary of the portions of its website governed by its privacy policy and provided a link to its complete “Terms of Use”. It also provided answers to frequently asked questions to assist users in navigating its privacy policy. Therefore, the Susan G. Komen Breast Cancer Foundation met the principle of privacy because the website clearly stated its privacy practices.

The Susan G. Komen Breast Cancer Foundation met the principle of attribution because it provided sources and dates for medical information. For example, under the heading “Understanding Breast Cancer” located on the left-hand navigation bar was a subheading titled “Treatments,” which provided definitions for different treatment options. Each treatment option was accompanied by a citation, which linked to a references page that included all of the information listed in the treatments section. Each webpage had a unique last modified date, which indicated how up-to-date information might be. The principle of attribution was therefore met because a full reference list was provided for all sources of medical information presented.

The principle of justifiability was met because the Susan G. Komen Breast Cancer Foundation provided justification and clear reasoning for claims made about specific treatment options. Treatments were itemized under the heading “Treatments” located on the left-hand navigation bar, and divided into the following subheadings: types of treatment, treatment options for breast cancer, factors that affect treatment and prognosis, clinical trials, other issues related to care and research tables. Within the description of Lumpectomy, a treatment option, the website outlined when Lumpectomy might be a viable treatment option and provided guidelines and a description of cosmetic issues that might affect decision-making. To support its claims, the webpage provided links to sources of information and underlined the consent of experts, such as

The National Cancer Institute. Therefore, the principle of justifiability was met because clear reasoning and justification was provided for each treatment choice.

The Susan G. Komen Breast Cancer Foundation met the principle of transparency because it provided users with valid contact details. Contact details were provided via the heading “Contact Us” located at the bottom of the front page. Contact information included the mailing address for the Susan G. Komen Breast Cancer Foundation’s headquarters, the phone number for its hotline, contact information for local affiliates and the phone number for its helpline. Users could submit comments directly to the website by filling out their comments on an online form. Links to social media were also included at the top of every page and included links to Facebook, Twitter and YouTube pages. Therefore, the principle of transparency was met because its website provided users with several means of contacting spokespersons.

The Susan G. Komen Breast Cancer Foundation met the principle of financial disclosure because it listed details of funding under the heading “Partners and Sponsors,” located on the front page. Partners and sponsors were divided into three categories: Million Dollar Council Elite, Race for the Cure National Sponsors, and Corporate Partners. As a result, the Susan G. Komen Breast Cancer Foundation met the principle of financial disclosure because it provided some information regarding funding.

The Susan G. Komen Breast Cancer Foundation did not meet the principle of advertising because no distinction was made between editorial and advertising content. Although a list of corporate sponsors was provided, there was no mention of whether or not those sponsors were also advertisers. Under the heading “Privacy Policy & Legal,” the Susan G. Komen Breast Cancer Foundation claimed to not endorse products sold by corporate partners. However, it did not provide details about advertising content that might be affiliated with sponsors. Therefore,

the advertising principle was not met because there was no clear distinction between content provided by the Susan G. Komen Foundation and advertisements.

## DISCERN

### Section 1: (Questions 1-8)

Using the DISCERN tool, a second content analysis was conducted on the Susan G. Komen Breast Cancer Foundation. The first question (“Are the aims clear?”) was given a rating of four indicating that its aims were mostly clear. Under the heading “About Us” located at the top of the front page was a description of Susan G. Komen, the inspiration for the foundation, and the promises or aims of the Susan G. Komen Breast Cancer Foundation. The foundation’s aims were described as “...to save lives, empower people, ensure quality care for all and energize science to find the cures” (Susan G. Komen for the cure, 2012). These aims were mostly clear although absent was how the Susan G. Komen Breast Cancer Foundation would execute its aims. Therefore, a high rating of four was given because the foundation’s aims were mostly clearly presented.

The second question (“Does it achieve its aims?”) was given a rating of five indicating that the Susan G. Komen Breast Cancer Foundation met its aims through the content posted on its website. The website described how cancer research supported by the Susan G. Komen Breast Cancer Foundation saves lives and empowers others. It also provided links to information on care and treatment and demonstrated its support for finding cures to breast cancer through research and grant opportunities. Therefore, a rating of five was given because the Susan G. Komen Breast Cancer Foundation met the aims it outlined on its website.

The third question (“Is it relevant?”) was given a rating five indicating that all of the content posted on the website was relevant to the Susan G. Komen Breast Cancer Foundation and its stated aims. Content included a guide to understanding breast cancer, information on diagnosis and treatment, and a list of resources. Therefore, a rating of five was given because all of the information posted related to breast cancer, support and research.

The seventh question (“Does it provide details of additional sources of support and information?”) was given a rating of five indicating that the Susan G. Komen Breast Cancer Foundation provided full details of additional sources of support and information apart from those provided by the organization itself. Under the heading “Resources” located on the front page additional websites on breast cancer were provided in conjunction with interactive tools and a guide to using the Internet to find health information. Under the heading “Breast Cancer Research” located on the front page a number of external research studies on the topic of breast cancer were also included.

## Section 2: (Questions 9-15)

The ninth question (“Does it describe how each treatment works?”) was given a rating of five indicating that each treatment was accompanied by a description of how the treatment works. For example, the description of chemotherapy included information on how the treatment works when used both before and after breast surgery. More specific information on chemotherapy for metastatic breast cancer was provided along with a step-by-step description, which was located under the subheading “Going Through Chemotherapy”. Therefore, a rating of five was given because each treatment included information about how it works.

The 10<sup>th</sup> question (“Does it describe the benefits of each treatment?”) was given a rating of five indicating that the Susan G. Komen Breast Cancer Foundation described the benefits of each treatment. For example, in its description of chemotherapy following breast surgery – adjuvant chemotherapy – it states “adjuvant chemotherapy helps lower the risk of recurrence by getting rid of cancer that might still be present in the body” (Susan G. Komen for the cure, 2012). Likewise, in its description of chemotherapy before breast surgery – neoadjuvant chemotherapy – it states “neoadjuvant chemotherapy can reduce the size of the tumor in the breast and/or in the lymph nodes, and make it easier to surgically remove the cancer” (Susan G. Komen for the cure, 2012). Therefore, a rating of five was given because each treatment was accompanied by a description of its benefits.

The 11<sup>th</sup> question (“Does it describe the risks of each treatment?”) was given a rating of five indicating that the Susan G. Komen Breast Cancer Foundation described the risks of each treatment. For example, the description of chemotherapy linked to a sub-page titled “Side Effects of Chemotherapy”, which included a description of both the short and long-term effects of chemotherapy. These ranged from hair loss, nausea and vomiting to early menopause and leukemia. A rating of five was given because a wide-range of risks was described for all treatment options listed by the Susan G. Komen Breast Cancer Foundation.

The 12<sup>th</sup> question (“Does it describe what would happen if no treatment is used?”) was given a rating of one indicting that the Susan G. Komen Breast Cancer Foundation did not describe what would happen if no treatment were used. It assumed that the user would consider using some form of treatment. Although the website provided a section titled “Things to Consider Before Treatment,” which was located under the heading “Treatment” found on the right hand navigation bar, these considerations were general and included things such as getting

the flu shot and arranging dental visits. Therefore, a rating of one was given because each treatment was not accompanied by a description of what might happen if no treatment is used.

The 13<sup>th</sup> question (“Does it describe how the treatment choices affect overall quality of life?”) was given a rating of three indicating that the Susan G. Komen Breast Cancer Foundation referenced quality of life in relation to treatment choices, but the information it provided was somewhat incomplete. Under the heading “Treatment” and under the subheading “Other Issues Related to Care,” was a section titled “Quality of Life Issues”. This section provided a brief description of quality of life and listed several quality of life side effects, such as depression, as a result of diagnosis and treatment. It also listed factors that improve quality of life and the positive effects of treatment on quality of life. A rating of three was given because the Susan G. Komen Breast Cancer Foundation did not describe how each treatment affects quality of life but rather how treatment in general might affect quality of life.

The 14<sup>th</sup> question (“Is it clear that there may be more than one possible treatment choice?”) was given a rating of five indicating that the Susan G. Komen Breast Cancer Foundation made it clear that there might be more than one possible treatment choice. Under the heading “Treatment” located on the right hand navigation bar, treatments were divided into the following categories: surgical, radiation therapy, chemotherapy, chemotherapy drugs, hormone therapies, targeted therapies, neoadjuvant therapies, personalized medicine and emerging therapies. Treatment options were further separated into treatments for different stages of cancer, cancer during pregnancy and male breast cancer. A list of clinical trials was also provided. Therefore a rating of five was given because it was clear that there might be more than one possible treatment choice.



The 16<sup>th</sup> question produced a rating of five indicating that the publication is good quality. A rating of five was given because thirteen questions rated high—four or above—while one question rated low—two or below.

#### Breast Cancer at About.com

Breast Cancer at About.com is written by Pam Stephan, a 9-year breast cancer survivor and provides information on breast cancer to anyone interested in learning more about it. Information on breast cancer can be accessed from the homepage as follows: Home>Health>Cancer>Breast Cancer. The website claims to follow the HONcode standard.

Breast Cancer at About.com met the authoritative principle because the qualifications of Pam Stephan, the author, were provided. Under the heading “Pam Stephen” located on the front page was a list of Pam Stephen’s experience with breast cancer, diagnosis and treatment, as well as her educational background. Therefore, the authoritative principle was met because the website established the author’s occupation, history and background.

Breast Cancer at About.com met the principle of complementarity because it provided information to support but not replace traditional sources of health information. Informational videos lead by Dr. V.K. Gadi, MD, PhD, were provided alongside a guide on breast cancer produced by Pam Stephan, the website’s content author. A banner located at the top of every page indicated that the Medical Review Board had reviewed the content, and a link to the Medical Review Board was included for further information. Where treatments were discussed, academic sources were included. Under the heading “Support and Resources” links to medical applications and other online sources of support were specified to complement the information listed. Therefore, the principle of complementarity was met because information was provided to

support traditional sources of breast cancer information.

Breast Cancer at About.com met the principle of privacy because it provided a privacy policy, which was linked to at the bottom of each page. The privacy policy included statements about the types of information that the website collects, how the information collected is used and what information might be collected by third parties or advertisements. It also included a section on other privacy considerations, such as legal privacy rights and compliance with the legal process. Therefore, the privacy principle was met because the website provided a thorough description of its privacy practices.

Breast Cancer at About.com met the attribution principle because medical information was cited and dates were provided for when information had last been updated. The webpage stated at the top of each page that information provided had been reviewed by the Medical Review Board, a board made up of medical experts from research institutions and hospitals across the United States. Where technical information or studies were included, a link to the information source was provided along with the date of publication. At the top of each page a unique last updated date was displayed, which let the user know when information had been updated. Therefore, the attribution principle was met because dates and sources were clearly stated.

The principle of justifiability was met because clear reasoning was provided for claims made about specific treatments. For example, in its description of surgical treatment options, the webpage states “You will have some choices about which kind of surgery to have, depending on the tumor size and location. If you have a mastectomy, reconstruction may also be an option” (Stephan, 2012). All claims were written in an objective tone and claims were supported by outside sources of information. Therefore, the principle of justifiability was met because clear

reasoning was provided for statements made about specific treatment options.

Breast Cancer at About.com met the principle of transparency because contact details were provided for the content author. Contact details included email and social media in the form of Facebook and Twitter. Although Breast Cancer at About.com met the principle of transparency by providing a means of contacting the website's spokesperson, it did not provide a telephone number or mailing address. Those without access to the Internet or those less digitally savvy might therefore find it challenging to make use of the contact information provided. Still, because contact information was made available the principle of transparency was met.

Breast Cancer at About.com did not meet the principle of financial disclosure because it did not state sources of financial support. Although the website claimed to comply with the HONcode and provided a link to a certificate that verified its compliance, financial information was not clearly presented. Financial information was not found under the website's ethics policy, patent information, user agreement or privacy policy. Therefore, the principle of financial disclosure was not met because in the case that financial information was included it was not easily visible.

The advertising principle was met by Breast Cancer at About.com because the website declared where advertising content might be hosted. Under the heading "Ethics Policy" located at the bottom of the front page it stated its conflict-of-interest policy and advertising policy. The advertising policy stated "All advertising content is clearly distinguished from the editorial content by the following labels: Advertisement, sponsored links, ads. We do not accept illegal advertisements or any advertisement that About.com feels is objectionable or in bad taste" (Stephan, 2012). Therefore, the advertising principle was met because a distinction was made between advertising content and editorial content.

## DISCERN

### Section 1: (Questions 1-8)

Using the DISCERN tool, a second content analysis was conducted on Breast Cancer at About.com. The first question (“Are the aims clear?”) was given a rating of four indicating that the aims expressed by Breast Cancer at About.com were mostly clear. Under the heading “Pam Stephan” and under the subheading “From Pam Stephan” was a list of some of the aims of Breast Cancer at About.com. Within this section, the website states “whether you are newly diagnosed with breast cancer, a concerned family member or friend, or someone who wants to reduce your risk of breast cancer this site is for you” (Stephan, 2012). It then states that the purpose of the website is to provide information to make better decisions, be encouraging and helpful. While the website did not clearly state its aims, it effectively communicated its aims through its key messages.

The second question (“Does it achieve its aims?”) was given a rating of five indicating that Breast Cancer at About.com achieved its aims as stated through its key messages. It provided a wide-range of information directed to helping users make informed decisions and provided videos, online forums and links to support groups in order to encourage users. Therefore, a rating of five was given because the website provided content that supported its purpose and aims as stated under the subheading “From Pam Stephan”.

The third question (“Is it relevant?”) was given a rating five indicating that all of the information presented by Breast Cancer at About.com was relevant to the website and its aims. Information included a description of breast cancer, common symptoms, diagnosis, treatments and prevention. Information was divided into common topics and tailored to distinct audiences ranging from those newly diagnosed to those experiencing life after treatment. Therefore, a

rating of five was given because all of the information was relevant to breast cancer and the aims of Breast Cancer at About.com.

The seventh question (“Does it provide details of additional sources of support and information?”) was given a rating of five indicating that Breast Cancer at About.com provided additional sources of support and information. Links to a number of additional sources were provided under the heading “Support and Resources” located on the front page. These included links to charities, volunteer organizations, support groups and social media. Links to articles were included to support information provided, particularly for treatment options. Therefore, a rating of five was given because additional sources of support were presented beyond the website itself.

## Section 2: (Questions 9-15)

The ninth question (“Does it describe how each treatment works?”) was given a rating of five indicating that each treatment was accompanied by a description of how the treatment works. For example, the website described the different forms of radiation therapy and explained the preparation for treatment, the treatment itself and the recovery process. In its description of partial breast radiation it states, “just as for whole breast radiation, a machine from outside your body will aim the energy, but it will focus on a limited area of your breast” (Stephan, 2012). Links were provided to supplement each description. Therefore, a rating of five was given because each treatment included a description of how the treatment works.

The 10<sup>th</sup> question (“Does it describe the benefits of each treatment?”) was given a rating of five indicating that benefits were described for each treatment option. For example, in the website’s description of partial breast radiation it states, “partial breast radiation limits damage to

healthy tissue, speeds recovery, and has few side effects” (Stephan, 2012). Similar descriptions of benefits were provided for each treatment option.

The 11<sup>th</sup> question (“Does it describe the risks of each treatment?”) was given a rating of five indicating that risks were described for each treatment listed. For example, in the website’s description of partial breast radiation it states, “External beam radiation may cause some side effects, such as fatigue, radiation dermatitis, fibrosis, swelling, and tenderness of the radiated area. If your underarm area is included in radiation, you may experience arm lymphedema. Most of these side effects will disappear in a few weeks or months after completing treatment” (Stephan, 2012). Therefore, a rating of five was given because full descriptions were provided for each treatment option.

The 12<sup>th</sup> question (“Does it describe what would happen if no treatment is used?”) was given a rating of one indicating that the website did not describe what would happen if no treatment was used for any of the treatments listed. Descriptions of treatments included side effects, benefits, things to consider and step-by-step descriptions of the course of treatment. The website assumed that the user would select some form of treatment and did not include information related to not using treatment. Therefore, a rating of one was given because no description was provided with regards to what might happen if no treatment were used.

The 13<sup>th</sup> question (“Does it describe how the treatment choices affect overall quality of life?”) was given a rating of three indicating that the website included references to overall quality of life but the information provided was unclear and somewhat incomplete. For instance under the heading “Treatments” two subheadings titled “Living with Breast Cancer” and “Emotional Impact of Diagnosis” were listed. The former included a list of effects of different treatment options as well as testimonials from breast cancer survivors on how they were affected

by their treatment choice. The latter discussed the emotional effects of treatment. Both included general information on how treatments can affect quality of life but information was not specific to the treatment options listed. Therefore, a rating of three was given because some information was missing from references to quality of life.

The 14<sup>th</sup> question (“Is it clear that there may be more than one possible treatment choice?”) was given a rating of five indicating that the website made it clear that there might be more than one possible treatment choice. Under the heading “Treatment Options” located on the front page five types of breast cancer treatments were described. These included: surgery, radiation, chemotherapy, targeted therapies and hormonal therapy. Each treatment included a breakdown of different options within each treatment choice. Therefore, a rating of five was given because the website made it clear that there might be more than one treatment choice.

The 16<sup>th</sup> question produced a rating of five indicating that the publication is good quality. A rating of five was given because ten questions rated high—four or above—while one question rated low—two or below.

## Results

This study reviewed two traditional online sources of breast cancer information and two non-traditional online sources of breast cancer information. Results of the comparison between the sources can be found in Tables 1-4 and in *Appendix B*. Non-traditional online health sources of breast cancer information met more HON principles than traditional online health sources of breast cancer information. The CIBC Breast Centre at St. Michael's Hospital met five out of eight HON principles, while PHAC met three out of eight HON principles. Both the Susan G. Komen Breast Cancer Foundation and Breast Cancer at About.com met seven out of eight HON principles. Common HON principles not met by both traditional sources were the principles of attribution and advertising policy. No differences were found in the principles of complementarity and transparency. HON principles that varied included the principle of financial disclosure, which was not met by the CIBC Breast Centre at St. Michael's Hospital but was met by PHAC, and the principles of privacy and justifiability, which were not met by PHAC but were met by the CIBC Breast Centre at St. Michael's Hospital. Regarding the non-traditional online health sources of breast cancer information, the only principles that varied were the principles of advertising policy and financial disclosure, the former not met by the Susan G. Komen Breast Cancer Foundation and the latter not met by Breast Cancer at About.com.

The second content analysis using the DISCERN tool revealed that of the sources reviewed in this study, the non-traditional online sources of breast cancer information had better content quality than the traditional online sources of breast cancer information. The results are presented in *Appendix B*. Like the previous content analysis, the non-traditional sources rated higher and shared more commonalities than the non-traditional sources. Both non-traditional sources had only one question where content quality was rated poorly or below two. The



traditional sources exhibited greater variation with the CIBC Breast Cancer at St. Michael's Hospital displaying eight DISCERN scores below two and six DISCERN scores above four, and PHAC displaying seven DISCERN scores below two and five DISCERN scores above four. In both non-traditional sources higher scores were found in section one, which addressed issues of reliability and assessed trustworthiness in comparison to section two, which focused on descriptions of treatment choices.

## HONcode

### Content Analysis: Traditional Online Health Sources

Table 1: CIBC Breast Centre at St. Michael's Hospital

<b>Authoritative</b>	Met
<b>Complementarity</b>	Met
<b>Privacy</b>	Met
<b>Attribution</b>	Not met
<b>Justifiability</b>	Met
<b>Transparency</b>	Met
<b>Financial Disclosure</b>	Not met
<b>Advertising Policy</b>	Not met

Table 2: Breast Cancer: Public Health Agency Canada

<b>Authoritative</b>	Not met
<b>Complementarity</b>	Met
<b>Privacy</b>	Not met

<b>Attribution</b>	Not met
<b>Justifiability</b>	Not met
<b>Transparency</b>	Met
<b>Financial Disclosure</b>	Met
<b>Advertising Policy</b>	Not met

## Content Analysis: Non-traditional Online Health Sources

Table 3: The Susan G. Komen Breast Cancer Foundation

<b>Authoritative</b>	Met
<b>Complementarity</b>	Met
<b>Privacy</b>	Met
<b>Attribution</b>	Met
<b>Justifiability</b>	Met
<b>Transparency</b>	Met
<b>Financial Disclosure</b>	Met
<b>Advertising Policy</b>	Not met

Table 4: Breast Cancer at About.com

<b>Authoritative</b>	Met
<b>Complementarity</b>	Met
<b>Privacy</b>	Met
<b>Attribution</b>	Met

<b>Justifiability</b>	Met
<b>Transparency</b>	Met
<b>Financial Disclosure</b>	Not met
<b>Advertising Policy</b>	Met

## DISCERN

\* A complete analysis of each source using the DISCERN tool can be found in *Appendix B*.

## Discussion

B.J. Fogg, a leading researcher on the topic of online credibility, writes that online credibility is about constructing websites that exude a sense of trustworthiness and expertise (Fogg, 2002). According to a survey conducted by Princeton Survey Research Associates, four out of five Internet users consider being able to trust the information on a website as important in deciding whether or not to visit a website (Princeton Research Associates, 2002). In theory, anyone can publish information online, which makes it difficult for consumers to sort out credible from non-credible information. As the popularity of the Internet as a health information source rises and consumer digital health widens, developing a critical eye for how consumers perceive online credibility may boost the ability of online health sources to compete in a market saturated with health information.

The findings of this study suggest that non-traditional online sources of breast cancer information project higher perceptions of credibility than traditional online sources of breast cancer information. This challenges the common conception of what distinguishes a credible from a non-credible information source. According to this study, non-traditional sources project greater credibility because they include more detailed descriptions of treatments and reference specific sources of information. The traditional sources in this study relied more heavily upon their ascribed authority as information sources and therefore did not always include details to substantiate or validate their claims. Since the non-traditional sources in this study were run by breast cancer survivors, or hosted by them, they projected greater “personal ascribed authority.” It is not surprising that consumers might find it more comfortable to receive information from someone who has been through the breast cancer journey. As the “academic wall” of traditional sources can sometimes diminish credibility since some patients will not (and some can not) read an academic journal article, regardless of how well it is researched and written. This has

important implications from a consumer health perspective, particularly if consumers are actively seeking health information online. If consumers perceive non-traditional sources to be more credible than traditional sources then traditional sources face a real barrier in their ability to disseminate important health information.

In order to remedy this, a more strategic approach to presenting online health information is needed. Firstly, online health information sources should consider displaying critical information on the front page where it is most visible and can be used by consumers to assess the information source's trustworthiness and expertise. If users are unlikely to search through a website beyond the front page, then it is essential that information be positioned where users are most likely to engage with content. A seemingly obvious observation, both the traditional and non-traditional online sources in this study failed at one point or another to clearly present information indicative of website quality.

Enhancing website navigability may also aid users in distinguishing credible from non-credible online sources. Websites that make browsing a difficult task do themselves a disservice by disabling users from reaching the right information, regardless of whether or not the information is present. For example, the CIBC Breast Centre at St. Michael's Hospital website was located several links away from the homepage, making it difficult to find information on breast cancer. Intuitive website navigation helps to ensure that users spot important information that ultimately influences their perception of the website's credibility and expertise. It also ensures that the website is able to communicate its key messages.

Anticipating and addressing potential concerns, such as concerns about financing and advertisements, and presenting answers clearly can enhance credibility. For example, if a website does not have any financial sponsors or agreements with third parties it should clearly state this.

Not addressing concerns, even if the concerns are not relevant, leaves room for uncertainty and eliminates the website's opportunity to defend itself, which diminishes website credibility. In a market saturated with competing information, websites must convince consumers that the information they present is trustworthy. If they don't, patients may wonder whether the website is sponsored by a pharmaceutical company or another organization with a vested interest in the information presented.

Citing sources of information enriches credibility and is equally important for websites that are traditionally regarded as credible. Neither of the traditional sources in this study met the authoritative principle because neither clearly presented the sources of medical information. Citing information allows users to find research related to the information presented and offers evidence that serves to validate the website's claims. It also enhances credibility by demonstrating objectivity and consideration for external points of view.

Similarly, "personalization" can be used to develop a sense of trustworthiness and expertise. The non-traditional online sources in this study used the names of women to enhance the personal relevance and emotional resonance of the texts. Information was presented as though a friend or acquaintance had prepared it, which contributed to the source's trustworthiness. Seeking a prominent personality who has been treated for breast cancer and including their name on the site can enhance credibility by establishing positive self-referential thinking.

Furthermore, displaying when individual pages were last modified eliminates guesswork and helps users gauge how up to date and therefore how credible information might be. Both traditional sources in this study received a poor DISCERN rating of two because neither clearly communicated when information had last been modified. Rather than listing last modified

information for the entire source on the front page, a better practice might be to list last modified information on each individual page. Both non-traditional sources received a high DISCERN rating of five because last modified information was included for each page. This enhanced credibility and authority by declaring that the information presented was up-to-date.

Likewise, written content that appeals to the largest intersection of users interested in breast cancer information enhances the website's credibility as well as its ability to disseminate information. With so many unique visitors, finding the right balance of information is critical. For example, if information is too wide-ranging the website risks losing its audience but if it is too narrow, its content loses its relevance. Most of the sources included in this study did not include information pertaining to consumers not using treatment. Of the sources studied, only the non-traditional sources included information associated with how treatment might affect overall quality of life. Writing for a wide audience enables websites to captivate and retain the attention of consumers, which in turn enhances perceptions of credibility.

Finally, there is a need to educate medical personnel about the utility, reliability and worth of websites – and to inform them about the importance of recommending the most reliable of these to their patients. Whether medical personnel like it or not, their patients ARE going to seek out information online, as supported by research presented in this paper, and it is incumbent on medical personnel to support this by providing information about the best sites.

## Conclusion

The Internet remains an important information source for individuals seeking health information (Schiavo, 2008, p.10). Health information on the Internet continues to vary in quality. This makes it difficult for users to identify sources that are credible and accurate. As consumer digital health increases in popularity it becomes more important to understand how projections of credibility might vary between different online health information sources. The findings of this study suggest that the overall quality of non-traditional online sources of breast cancer information is better than traditional online sources of breast cancer information. Non-traditional online sources of breast cancer were more compliant with HONcode and its principles and had higher DISCERN scores. Traditional online sources of breast cancer information were less compliant with HONcode and its principles and had lower DISCERN scores.

The present study was limited by several factors. It studied only four online sources of breast cancer information and therefore its findings may not be true for all traditional and non-traditional online sources of breast cancer information. Another limitation was that the content quality of each source was assessed using HONcode and its principles, and DISCERN. Both tools were restricted to specific criteria and neither covered all the factors that might affect perceptions of credibility. While every effort was made to assess each source objectively, the overall ratings depended on the texts of each medium as they were understood by the researcher. Previous studies indicate that DISCERN ratings are significantly correlated with perceptions of credibility and support the notion that a high DISCERN rating is linked to compliance with the HONcode and its principles, as this study suggests (Khazaal et.al, 2012). Further studies might assess how a large sample of consumers perceives the credibility of online sources of breast cancer information and whether perceptions and quality ratings differ between users. A more



diverse group of users with different demographic credentials would also enhance studies on this topic.

This study suggests that projections of credibility do differ between traditional and non-traditional online health sources of breast cancer information, with non-traditional sources demonstrating more positive results overall. If non-traditional online sources of health information have become the new ‘credible’ sources, the implications are considerable for traditional online health sources. Consequently, it is important that traditional sources better understand these implications in order to make appropriate alterations. Otherwise they could see their support erode, leading to a lack of consumer trust.

As Internet use for health information seeking and consumer digital health increases in popularity, there is a tremendous need for discussion on this topic, especially given the importance of accessing credible health information and its impact on consumer decision-making.

## *Appendix A*

### CIBC Breast Centre at St. Michael's Hospital—*Hospital*

- The CIBC Breast Centre is affiliated with St. Michael's Hospital and offers a comprehensive range of assessment, diagnostic and treatment services for women dealing with the effects of breast cancer (St. Michael's Hospital, 2012).

### Breast Cancer: Public Health Agency Canada—*Government agency*

- The Public Health Agency of Canada is a federal government agency focused on protecting the health of Canadians through leadership, partnership and action in public health (Public Health Agency of Canada, 2012).

### Non-traditional online health sources:

#### The Susan G. Komen Breast Cancer Foundation—*Not-for-profit*

- The Susan G. Komen Breast Cancer Foundation is a global leader of the breast cancer movement and the world's largest grassroots network of breast cancer survivors and activists (Susan G. Komen for the cure, 2012).

#### Breast Cancer at About.com—*Blog*

- Guided by a breast cancer survivor, Breast Cancer at About.com provides information to patients, their families, and anyone interested in learning more about breast cancer (Stephan, 2012).

## The HON principles:

### 1. Authoritative

- Shows the qualifications of the author(s).
- E.g., Establishes the author(s) occupation, history, background.

### 2. Complementarity

- Provides information to support but not replace traditional health sources.
- E.g., References traditional sources of information, such as: Hospitals, national institutions, universities and government agencies.

### 3. Privacy

- Demonstrates respect for privacy of the site user.
- E.g., Establishes a statement of privacy practices.

### 4. Attribution

- Cites the sources and dates of medical information.
- E.g., Clearly establishes the sources of medical information.

### 5. Justifiability

- Provides justification for claims/demonstrates balanced and objective claims.
- E.g., Provides clear reasoning for claims about a specific treatment.

### 6. Transparency

- Provides valid contact details.
- E.g., Provides a means of contacting webmasters or spokespersons.

### 7. Financial disclosure

- Provides details of funding.

- E.g., Clearly states sources of financial support.

## 8. Advertising policy

- Clearly distinguishes advertising from editorial content.
- E.g., Declares where advertising is hosted on the site.

The DISCERN tool:

### SECTION 1: Is the publication reliable?

#### 1. Are the aims clear?

##### Rating this question

No		Partially		Yes
1	2	3	4	5

**HINT:** Look for a clear indication at the beginning of the publication of:

What it is about

What it is meant to cover (and what topics are meant to be excluded)

Who might find it useful

If the answer to "1" is 'No', go directly to **Question 3**

#### 2. Does it achieve its aims?

##### Rating this question

No		Partially		Yes
1	2	3	4	5

**HINT:** Consider whether the publication provides the information it aimed to as outlined in **Question 1**

#### 3. Is it relevant?

##### Rating this question

No		Partially		Yes
1	2	3	4	5

**HINT:** Consider whether:

- The publication addresses the questions that readers might ask.
- Recommendations and suggestions concerning treatment choices are realistic or appropriate.

#### 4. Is it clear what sources of information were used to compile the publication (other than the author or producer)?

### Rating this question

No		Partially		Yes
1	2	3	4	5

#### HINT

- Check whether the main claims or statements made about treatment choices are accompanied by a reference to the sources used as evidence, e.g. a research study or expert opinion.
- Look for a means of checking the sources used such as a bibliography/reference list or the addresses of the experts or organisations quoted, or external links to the online sources.

Rating note: In order to score a full '5' the publication should fulfil both hints. Lists of **additional** sources of support and information (Question 7) are not necessarily sources of **evidence** for the current publication.

### 5. Is it clear when the information used or reported in the publication was produced?

#### Rating this question

No		Partially		Yes
1	2	3	4	5

#### HINT: Look for:

- Dates of the main sources of information used to compile the publication
- date of any revisions of the publication (but not dates of reprinting in the case of print publications)
- Date of publication (copyright date).

Rating note: The hints are placed in order of importance - in order to score a full '5' the dates relating to the first hint should be found.

### 6. Is it balanced and unbiased?

#### Rating this question

No		Partially		Yes
1	2	3	4	5

#### HINT: Look for:

- A clear indication of whether the publication is written from a personal or objective point of view
- Evidence that a *range* of sources of information was used to compile the publication, e.g. more than one research study or expert
- Evidence of an external assessment of the publication.

Be wary if:

- The publication focuses on the advantages or disadvantages of one particular treatment choice without reference to other possible choices

- The publication relies primarily on evidence from single cases (which may not be typical of people with this condition or of responses to a particular treatment)
- The information is presented in a sensational, emotive or alarmist way.

## 7. Does it provide details of additional sources of support and information?

### Rating this question

No		Partially		Yes
1	2	3	4	5

**HINT** Look for suggestions for further reading or for details of other organisations providing advice and information about the condition and treatment choices.

## 8. Does it refer to areas of uncertainty?

### Rating this question

No		Partially		Yes
1	2	3	4	5

**HINT**

- Look for discussion of the gaps in knowledge or differences in expert opinion concerning treatment choices.
- Be wary if the publication implies that a treatment choice affects everyone in the same way, e.g. 100% success rate with a particular treatment.

## 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?

### Rating this question

No		Partially		Yes
1	2	3	4	5

**HINT:** Look for a description of how a treatment acts on the body to achieve its effect.

## 10. Does it describe the benefits of each treatment?

### Rating this question

No		Partially		Yes
1	2	3	4	5

**HINT:** Benefits can include controlling or getting rid of symptoms, preventing recurrence of the condition and eliminating the condition, both short-term and long-term.

## 11. Does it describe the risks of each treatment?

### Rating this question

No		Partially		Yes
1	2	3	4	5

**HINT:** Risks can include side-effects, complications and adverse reactions to treatment, both short-term and long-term.

## 12. Does it describe what would happen if no treatment is used?

### Rating this question

No		Partially		Yes
1	2	3	4	5

**HINT:** Look for a description of the risks and benefits of postponing treatment, of watchful waiting (i.e. monitoring how the condition progresses without treatment) or of permanently forgoing treatment.

## 13. Does it describe how the treatment choices affect overall quality of life?

### Rating this question

No		Partially		Yes
1	2	3	4	5

**HINT:** Look for:

- Description of the effects of the treatment choices on day-to-day activity
- Description of the effects of the treatment choices on relationships with family, friends and carers.

## 14. Is it clear that there may be more than one possible treatment choice?

### Rating this question

No		Partially		Yes
1	2	3	4	5

**HINT:** Look for:

- A description of who is most likely to benefit from each treatment choice mentioned, and under what circumstances
- Suggestions of alternatives to consider or investigate further (including choices not fully described in the publication) before deciding whether to select or reject a particular treatment choice.

## 15. Does it provide support for shared decision-making?

### Rating this question

No		Partially		Yes
1	2	3	4	5

**HINT** Look for suggestions of things to discuss with family, friends, doctors or other health professionals concerning treatment choices.

## 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**

**Rating this question**

<b>Low</b>		<b>Moderate</b>		<b>High</b>
<i>Serious or extensive shortcomings</i>		<i>Potentially important but not serious shortcomings</i>		<i>Minimal shortcomings</i>
1	2	3	4	5

(DISCERN, 2012)



## Appendix B

### Summary of DISCERN scores

#### CIBC Breast Centre at St. Michael's Hospital

##### 1. Are the aims clear?

5: Yes - the publication has clear aims.  
2 - 4: Partially - the publication has aims but they are unclear or incomplete.  
1: No - the publication does not include any indication of its aims.

Rating = 4

##### 2. Does it achieve its aims?

5: Yes - all the information you were expecting from a description of the aims has been provided.  
2 - 4: Partially - some of the information you were expecting from the aims has been provided.  
1: No - none of the information you were expecting from the aims has been provided.

Rating = 3

##### 3. Is it relevant?

5: Yes - the information is relevant.  
2-4: Partially - the information is relevant to some extent.  
1: No - the information is not at all relevant.

Rating = 5

##### 4. Is it clear what sources of information were used to compile the publication (other than the author or producer)?

5: Yes - the sources of evidence are very clear and the publication

enables you to link the source mentioned in the text to a full reference at the end of the publication or to another online source of information. It is possible that a publication referring to a single source in both the text and the reference list or link will rate high on this question. Judging the quality of a publication based on a single source of information is a separate issue that is addressed in Question 6.

2 - 4: Partially - the sources of evidence are clear to some extent. Give a partial rating if one of the hints is fulfilled. You may also give a partial rating to a publication which quotes a reference in the text for some but not all of the main statements or 'facts' about treatment choices, although you will need to use your judgment to decide when a reference would be expected.

1: No - no sources of evidence for the information are mentioned.

Rating = 1

5. Is it clear when the information used or reported in the publication was produced?

5: Yes - dates for all acknowledged sources are clear.

2 - 4: Partially - only the date of the publication itself is clear, or dates for some but not all acknowledged sources have been given.

1: No - no dates have been given.

Rating = 2

6. Is it balanced and unbiased?

5: Yes - the information is completely balanced and unbiased.

2 - 4: Partially - some aspects of the information are unbalanced or biased.

1: No - the information is completely unbalanced or biased.

Rating = 4

7. Does it provide details of additional sources of support and information?

5: Yes - the publication provides full details of any additional source other than local branches of the same organization.

2 - 4: Partially - the publication provides details of an additional source or sources, but the details are incomplete or consist only of local branches of the same organization.

1: No - no additional sources of information are provided.

Rating = 5

8. Does it refer to areas of uncertainty?

5: Yes - the publication includes a clear reference to any uncertainty regarding treatment choices: this may be linked to each treatment choice or may be covered in a more general discussion or summary of the choices mentioned in the publication.

2 - 4: Partially - uncertainty is mentioned but the information is unclear or incomplete.

1: No - no uncertainty about treatment choices is mentioned.

Rating = 1

9. Does it describe how each treatment works?

5: Yes - the description of each treatment includes details of how it works.

2 - 4: Partially - the description of some but not all of the treatments includes details of how treatment works, or the details provided are unclear or incomplete.

1: No - none of the descriptions about treatments include details of how treatment works.

Rating = 5

10. Does it describe the benefits of each treatment?

5: Yes - a benefit is described for each treatment.

2 - 4: Partially - a benefit is described for some but not all of the treatments.

1: No - no benefits are described for any of the treatments.

Rating = 1

11. Does it describe the risks of each treatment?

5: Yes - a risk is described for each treatment.  
2 - 4: Partially - a risk is described for some but not all of the treatments.  
1: No - no risks are described for any of the treatments.

Rating = 2

12. Does it describe what would happen if no treatment is used?

5: Yes - there is a clear description of a risk or a benefit associated with any no treatment option.  
2 - 4: Partially - a risk or benefit associated with a no treatment option is mentioned, but the information is unclear or incomplete.  
1: No - the publication does not include any reference to the risks or benefits of no treatment options.

Rating = 1

13. Does it describe how the treatment choices affect overall quality of life?

5: Yes - the publication includes a clear reference to overall quality of life in relation to any of the treatment choices mentioned.  
2 - 4: Partially - the publication includes a reference to overall quality of life in relation to treatment choices, but the information is unclear or incomplete.  
1: No - there is no reference to overall quality of life in relation to treatment choices.

Rating = 1

14. Is it clear that there may be more than one possible treatment choice?

5: Yes - the publication makes it very clear that there may be more than one possible treatment choice.  
2 - 4: Partially - the publication indicates that there may be more than one possible choice, but the information is unclear or incomplete.

1: No - the publication does not give any indication that there may be a choice about treatment.

Rating = 5

15. Does it provide support for shared decision-making?

5: Yes - the publication provides very good support for shared decision-making.

2 - 4: Partially - the publication provides some support for shared decision-making.

1: No - the publication does not provide any support for shared decision-making.

Rating = 1

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

High (5) - the publication rated high (4 or above) on the majority of questions. A high overall quality rating indicates the publication is 'good' quality - it is a useful and appropriate source of information about treatment choices.

Moderate (3) - the publication rated high and low on a similar number of questions, or the majority of questions rated in the mid-ranges (3). A moderate overall quality rating indicates the publication is 'fair' quality - it is a useful source of information about treatment choices but has some limitations. Additional information or support would definitely be needed.

Low (1) - the publication rated low (2 or below) on the majority of questions. A low overall quality rating indicates the publication is 'poor' quality - it has serious shortcomings and is not a useful or appropriate source of information about treatment choices. It is unlikely to be of any benefit and should not be used.

Rating = 1

## Breast Cancer: Public Health Agency Canada

### 1. Are the aims clear?

5: Yes - the publication has clear aims.

2 - 4: Partially - the publication has aims but they are unclear or incomplete.

1: No - the publication does not include any indication of its aims.

Rating = 5

### 2. Does it achieve its aims?

5: Yes - all the information you were expecting from a description of the aims has been provided.

2 - 4: Partially - some of the information you were expecting from the aims has been provided.

1: No - none of the information you were expecting from the aims has been provided.

Rating = 3

### 3. Is it relevant?

5: Yes - the information is relevant.

2-4: Partially - the information is relevant to some extent.

1: No - the information is not at all relevant.

Rating = 5

### 4. Is it clear what sources of information were used to compile the publication (other than the author or producer)?

5: Yes - the sources of evidence are very clear and the publication enables you to link the source mentioned in the text to a full reference at the end of the publication or to another online source of information. It is possible that a publication referring to a single source in both the text and the reference list or link will rate high on this question. Judging the quality of a publication based on a single source of information is a separate issue that is addressed in

Question 6.

2 - 4: Partially - the sources of evidence are clear to some extent.  
Give a partial rating if one of the hints is fulfilled. You may also give a partial rating to a publication which quotes a reference in the text for some but not all of the main statements or 'facts' about treatment choices, although you will need to use your judgment to decide when a reference would be expected.

1: No - no sources of evidence for the information are mentioned.

Rating = 3

5. Is it clear when the information used or reported in the publication was produced?

5: Yes - dates for all acknowledged sources are clear.

2 - 4: Partially - only the date of the publication itself is clear, or dates for some but not all acknowledged sources have been given.

1: No - no dates have been given.

Rating = 2

6. Is it balanced and unbiased?

5: Yes - the information is completely balanced and unbiased.

2 - 4: Partially - some aspects of the information are unbalanced or biased.

1: No - the information is completely unbalanced or biased.

Rating = 4

7. Does it provide details of additional sources of support and information?

5: Yes - the publication provides full details of any additional source other than local branches of the same organization.

2 - 4: Partially - the publication provides details of an additional source or sources, but the details are incomplete or consist only of local branches of the same organization.

1: No - no additional sources of information are provided.

Rating = 5

8. Does it refer to areas of uncertainty?

5: Yes - the publication includes a clear reference to any uncertainty regarding treatment choices: this may be linked to each treatment choice or may be covered in a more general discussion or summary of the choices mentioned in the publication.

2 - 4: Partially - uncertainty is mentioned but the information is unclear or incomplete.

1: No - no uncertainty about treatment choices is mentioned.

Rating = 1

9. Does it describe how each treatment works?

5: Yes - the description of each treatment includes details of how it works.

2 - 4: Partially - the description of some but not all of the treatments includes details of how treatment works, or the details provided are unclear or incomplete.

1: No - none of the descriptions about treatments include details of how treatment works.

Rating = 3

10. Does it describe the benefits of each treatment?

5: Yes - a benefit is described for each treatment.

2 - 4: Partially - a benefit is described for some but not all of the treatments.

1: No - no benefits are described for any of the treatments.

Rating = 2

11. Does it describe the risks of each treatment?

5: Yes - a risk is described for each treatment.

2 - 4: Partially - a risk is described for some but not all of the treatments.

1: No - no risks are described for any of the treatments.

Rating = 1



12. Does it describe what would happen if no treatment is used?

5: Yes - there is a clear description of a risk or a benefit associated with any no treatment option.  
2 - 4: Partially - a risk or benefit associated with a no treatment option is mentioned, but the information is unclear or incomplete.  
1: No - the publication does not include any reference to the risks or benefits of no treatment options.

Rating = 1

13. Does it describe how the treatment choices affect overall quality of life?

5: Yes - the publication includes a clear reference to overall quality of life in relation to any of the treatment choices mentioned.  
2 - 4: Partially - the publication includes a reference to overall quality of life in relation to treatment choices, but the information is unclear or incomplete.  
1: No - there is no reference to overall quality of life in relation to treatment choices.

Rating = 1

14. Is it clear that there may be more than one possible treatment choice?

5: Yes - the publication makes it very clear that there may be more than one possible treatment choice.  
2 - 4: Partially - the publication indicates that there may be more than one possible choice, but the information is unclear or incomplete.  
1: No - the publication does not give any indication that there may be a choice about treatment.

Rating = 5

15. Does it provide support for shared decision-making?

5: Yes - the publication provides very good support for shared decision-making.

2 - 4: Partially - the publication provides some support for shared decision-making.

1: No - the publication does not provide any support for shared decision-making.

Rating = 2

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

High (5) - the publication rated high (4 or above) on the majority of questions. A high overall quality rating indicates the publication is 'good' quality - it is a useful and appropriate source of information about treatment choices.

Moderate (3) - the publication rated high and low on a similar number of questions, or the majority of questions rated in the mid-ranges (3). A moderate overall quality rating indicates the publication is 'fair' quality - it is a useful source of information about treatment choices but has some limitations. Additional information or support would definitely be needed.

Low (1) - the publication rated low (2 or below) on the majority of questions. A low overall quality rating indicates the publication is 'poor' quality - it has serious shortcomings and is not a useful or appropriate source of information about treatment choices. It is unlikely to be of any benefit and should not be used.

Rating = 1

### The Susan G. Komen Breast Cancer Foundation

1. Are the aims clear?

5: Yes - the publication has clear aims.

2 - 4: Partially - the publication has aims but they are unclear or incomplete.

1: No - the publication does not include any indication of its aims.

	Rating = 4
2. Does it achieve its aims?	
5: Yes - all the information you were expecting from a description of the aims has been provided.	
2 - 4: Partially - some of the information you were expecting from the aims has been provided.	
1: No - none of the information you were expecting from the aims has been provided.	
	Rating = 5
3. Is it relevant?	
5: Yes - the information is relevant.	
2-4: Partially - the information is relevant to some extent.	
1: No - the information is not at all relevant.	
	Rating = 5
4. Is it clear what sources of information were used to compile the publication (other than the author or producer)?	
5: Yes - the sources of evidence are very clear and the publication enables you to link the source mentioned in the text to a full reference at the end of the publication or to another online source of information. It is possible that a publication referring to a single source in both the text and the reference list or link will rate high on this question. Judging the quality of a publication based on a single source of information is a separate issue that is addressed in Question 6.	
2 - 4: Partially - the sources of evidence are clear to some extent. Give a partial rating if one of the hints is fulfilled. You may also give a partial rating to a publication which quotes a reference in the text for some but not all of the main statements or 'facts' about treatment choices, although you will need to use your judgment to decide when a reference would be expected.	
1: No - no sources of evidence for the information are mentioned.	

	Rating = 5
5. Is it clear when the information used or reported in the publication was produced?	
5: Yes - dates for all acknowledged sources are clear. 2 - 4: Partially - only the date of the publication itself is clear, or dates for some but not all acknowledged sources have been given. 1: No - no dates have been given.	
	Rating = 5
6. Is it balanced and unbiased?	
5: Yes - the information is completely balanced and unbiased. 2 - 4: Partially - some aspects of the information are unbalanced or biased. 1: No - the information is completely unbalanced or biased.	
	Rating = 4
7. Does it provide details of additional sources of support and information?	
5: Yes - the publication provides full details of any additional source other than local branches of the same organization. 2 - 4: Partially - the publication provides details of an additional source or sources, but the details are incomplete or consist only of local branches of the same organization. 1: No - no additional sources of information are provided.	
	Rating = 5
5: Yes - the publication has clear aims. 2 - 4: Partially - the publication has aims but they are unclear or incomplete. 1: No - the publication does not include any indication of its aims.	
	Rating = 4

8. Does it refer to areas of uncertainty?

5: Yes - the publication includes a clear reference to any uncertainty regarding treatment choices: this may be linked to each treatment choice or may be covered in a more general discussion or summary of the choices mentioned in the publication.

2 - 4: Partially - uncertainty is mentioned but the information is unclear or incomplete.

1: No - no uncertainty about treatment choices is mentioned.

Rating = 5

9. Does it describe how each treatment works?

5: Yes - the description of each treatment includes details of how it works.

2 - 4: Partially - the description of some but not all of the treatments includes details of how treatment works, or the details provided are unclear or incomplete.

1: No - none of the descriptions about treatments include details of how treatment works.

Rating = 5

10. Does it describe the benefits of each treatment?

5: Yes - a benefit is described for each treatment.

2 - 4: Partially - a benefit is described for some but not all of the treatments.

1: No - no benefits are described for any of the treatments.

Rating = 5

11. Does it describe the risks of each treatment?

5: Yes - a risk is described for each treatment.

2 - 4: Partially - a risk is described for some but not all of the treatments.

1: No - no risks are described for any of the treatments.

Rating = 5

12. Does it describe what would happen if no treatment is used?

5: Yes - there is a clear description of a risk or a benefit associated with any no treatment option.  
2 - 4: Partially - a risk or benefit associated with a no treatment option is mentioned, but the information is unclear or incomplete.  
1: No - the publication does not include any reference to the risks or benefits of no treatment options.

Rating = 1

13. Does it describe how the treatment choices affect overall quality of life?

5: Yes - the publication includes a clear reference to overall quality of life in relation to any of the treatment choices mentioned.  
2 - 4: Partially - the publication includes a reference to overall quality of life in relation to treatment choices, but the information is unclear or incomplete.  
1: No - there is no reference to overall quality of life in relation to treatment choices.

Rating = 3

14. Is it clear that there may be more than one possible treatment choice?

5: Yes - the publication makes it very clear that there may be more than one possible treatment choice.  
2 - 4: Partially - the publication indicates that there may be more than one possible choice, but the information is unclear or incomplete.  
1: No - the publication does not give any indication that there may be a choice about treatment.

Rating = 5

15. Does it provide support for shared decision-making?

5: Yes - the publication provides very good support for shared decision-making.

2 - 4: Partially - the publication provides some support for shared decision-making.

1: No - the publication does not provide any support for shared decision-making.

Rating = 5

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

High (5) - the publication rated high (4 or above) on the majority of questions. A high overall quality rating indicates the publication is 'good' quality - it is a useful and appropriate source of information about treatment choices.

Moderate (3) - the publication rated high and low on a similar number of questions, or the majority of questions rated in the mid-ranges (3). A moderate overall quality rating indicates the publication is 'fair' quality - it is a useful source of information about treatment choices but has some limitations. Additional information or support would definitely be needed.

Low (1) - the publication rated low (2 or below) on the majority of questions. A low overall quality rating indicates the publication is 'poor' quality - it has serious shortcomings and is not a useful or appropriate source of information about treatment choices. It is unlikely to be of any benefit and should not be used.

Rating = 5

### Breast Cancer at About.com

1. Are the aims clear?

5: Yes - the publication has clear aims.

2 - 4: Partially - the publication has aims but they are unclear or incomplete.

1: No - the publication does not include any indication of its aims.

Rating = 4

2. Does it achieve its aims?

5: Yes - all the information you were expecting from a description of the aims has been provided.

2 - 4: Partially - some of the information you were expecting from the aims has been provided.

1: No - none of the information you were expecting from the aims has been provided.

Rating = 5

3. Is it relevant?

5: Yes - the information is relevant.

2-4: Partially - the information is relevant to some extent.

1: No - the information is not at all relevant.

Rating = 5

4. Is it clear what sources of information were used to compile the publication (other than the author or producer)?

5: Yes - the sources of evidence are very clear and the publication enables you to link the source mentioned in the text to a full reference at the end of the publication or to another online source of information. It is possible that a publication referring to a single source in both the text and the reference list or link will rate high on this question. Judging the quality of a publication based on a single source of information is a separate issue that is addressed in Question 6.

2 - 4: Partially - the sources of evidence are clear to some extent. Give a partial rating if one of the hints is fulfilled. You may also give a partial rating to a publication which quotes a reference in the text for some but not all of the main statements or 'facts' about treatment choices, although you will need to use your judgment to decide when a reference would be expected.



1: No - no sources of evidence for the information are mentioned.

Rating = 3

5. Is it clear when the information used or reported in the publication was produced?

5: Yes - dates for all acknowledged sources are clear.

2 - 4: Partially - only the date of the publication itself is clear, or dates for some but not all acknowledged sources have been given.

1: No - no dates have been given.

Rating = 5

6. Is it balanced and unbiased?

5: Yes - the information is completely balanced and unbiased.

2 - 4: Partially - some aspects of the information are unbalanced or biased.

1: No - the information is completely unbalanced or biased.

Rating = 4

7. Does it provide details of additional sources of support and information?

5: Yes - the publication provides full details of any additional source other than local branches of the same organization.

2 - 4: Partially - the publication provides details of an additional source or sources, but the details are incomplete or consist only of local branches of the same organization.

1: No - no additional sources of information are provided.

Rating = 5

8. Does it refer to areas of uncertainty?

5: Yes - the publication includes a clear reference to any uncertainty regarding treatment choices: this may be linked to each treatment choice or may be covered in a more general discussion or summary of the choices mentioned in the publication.

<p>2 - 4: Partially - uncertainty is mentioned but the information is unclear or incomplete.</p> <p>1: No - no uncertainty about treatment choices is mentioned.</p>	<div></div> <div></div> <div>Rating = 3</div>
<p>9. Does it describe how each treatment works?</p> <p>5: Yes - the description of each treatment includes details of how it works.</p> <p>2 - 4: Partially - the description of some but not all of the treatments includes details of how treatment works, or the details provided are unclear or incomplete.</p> <p>1: No - none of the descriptions about treatments include details of how treatment works.</p>	<div></div> <div></div> <div></div> <div>Rating = 5</div>
<p>10. Does it describe the benefits of each treatment?</p> <p>5: Yes - a benefit is described for each treatment.</p> <p>2 - 4: Partially - a benefit is described for some but not all of the treatments.</p> <p>1: No - no benefits are described for any of the treatments.</p>	<div></div> <div></div> <div></div> <div>Rating = 5</div>
<p>11. Does it describe the risks of each treatment?</p> <p>5: Yes - a risk is described for each treatment.</p> <p>2 - 4: Partially - a risk is described for some but not all of the treatments.</p> <p>1: No - no risks are described for any of the treatments.</p>	<div></div> <div></div> <div></div> <div>Rating = 5</div>
<p>12. Does it describe what would happen if no treatment is used?</p> <p>5: Yes - there is a clear description of a risk or a benefit associated with any no treatment option.</p>	<div></div>

<p>2 - 4: Partially - a risk or benefit associated with a no treatment option is mentioned, but the information is unclear or incomplete.</p> <p>1: No - the publication does not include any reference to the risks or benefits of no treatment options.</p>	
	Rating = 1

13. Does it describe how the treatment choices affect overall quality of life?

<p>5: Yes - the publication includes a clear reference to overall quality of life in relation to any of the treatment choices mentioned.</p> <p>2 - 4: Partially - the publication includes a reference to overall quality of life in relation to treatment choices, but the information is unclear or incomplete.</p> <p>1: No - there is no reference to overall quality of life in relation to treatment choices.</p>	
	Rating = 3

14. Is it clear that there may be more than one possible treatment choice?

<p>5: Yes - the publication makes it very clear that there may be more than one possible treatment choice.</p> <p>2 - 4: Partially - the publication indicates that there may be more than one possible choice, but the information is unclear or incomplete.</p> <p>1: No - the publication does not give any indication that there may be a choice about treatment.</p>	
	Rating = 5

15. Does it provide support for shared decision-making?

<p>5: Yes - the publication provides very good support for shared decision-making.</p> <p>2 - 4: Partially - the publication provides some support for shared decision-making.</p> <p>1: No - the publication does not provide any support for shared decision-making.</p>	

Rating = 5

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

High (5) - the publication rated high (4 or above) on the majority of questions. A high overall quality rating indicates the publication is 'good' quality - it is a useful and appropriate source of information about treatment choices.

Moderate (3) - the publication rated high and low on a similar number of questions, or the majority of questions rated in the mid-ranges (3). A moderate overall quality rating indicates the publication is 'fair' quality - it is a useful source of information about treatment choices but has some limitations. Additional information or support would definitely be needed.

Low (1) - the publication rated low (2 or below) on the majority of questions. A low overall quality rating indicates the publication is 'poor' quality - it has serious shortcomings and is not a useful or appropriate source of information about treatment choices. It is unlikely to be of any benefit and should not be used.

Rating = 5

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