Navigating the Internet in Patient Physician Collaboration

BY

PARIS-ANN INGLEDEW
BSc, University of Calgary, 1998
M.D., University of British Columbia, 2002

THESIS

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Defense Committee:

Ilene Harris, Thesis Chair and Advisor
Glenn Regehr, University of British Columbia
Ara Tekian

This thesis is dedicated to my husband, Todd Ingledew, and my daughters, Reese and Tory Ingledew. You are the loves of my life. Thank you also to my parents Margaret-Ann and Andrew Gfeller for your unconditional love and support.

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SUMMARY

In order for patients and physicians to engage in models of shared decision making, it is essential for physicians to be able to understand and integrate the baseline knowledge of patients into each encounter. Increasingly patients are turning to the internet to gain knowledge about their medical problems. While the internet provides an infinite information resource, it may be difficult for patients to make judgments about the quality of the information. As a result, patients may come to a medical encounter with knowledge that is inapplicable or even inaccurate. There is evidence to suggest that very few physicians take the time to ask patients about their sources of information or integrate it into the encounter. This can negatively impact the patient and physician relationship.

A potential way to improve patient and physician interactions is to define the competencies related to the ability of physicians to aid patients in the interpretation and translation of web-based materials. At present, post-graduate medical training competency frameworks make little mention of patient education and there is no specific mention of competencies related to the integration and interpretation of web-based information. Thus, as a starting point for a program of research designed to formulate articulate best practices related to patient education, we propose to develop a framework that can be used by physicians and patients to evaluate web-based resources. To develop this framework, we performed a focused review of the literature to gain an understanding of existing approaches to evaluation of web-based resources. We developed an evaluation tool, based on currently available tools, using the best attributes of current tools and addressing recognized limitations in these tools. By

SUMMARY (continued)

drawing on the principles of design-based research, we iteratively evaluated and improved the tool through its application for two specific disease areas.

The products of this research are a robust tool that may be used by both physicians and patients to evaluate the quality of web-based resources. Through development of the tool, this research results in articulation of broad categories that may be useful for the assessment of the quality of web-based materials. Ultimately, this particular research will serve to inform a larger program of research which will define the skills required by physicians to collaborate with patients in interpretation of and evaluation of web-based materials.

I. INTRODUCTION/RATIONALE

A significant body of literature indicates that effective patient and physician collaboration and shared decision making increases patient satisfaction, improves health care outcomes and decreases health care costs (Wald, Dube, and Anthony 2007) Cho and colleagues comment that informed patients are more "involved in the decision making process, are more satisfied with their treatment choices, and communicate better with their families" (Cho et al. 2011). Charles and colleagues comment that in shared decision making, "the information exchange is two-way" (Charles, Gafni, and Whelan 1999) and "the intention is that patients and health professionals share both the process of decision making and ownership of the decision made" (Coulter, Entwistle, and Gilbert 1999)(Charles, Gafni, and Whelan 2004). Not only does the physician provide information relevant to make decisions about care and management, but the patient must also share relevant information that allows both the physician and patient to evaluate care and management within the context of the specific situation relevant to the patient (Charles, Gafni, and Whelan 1997). Thus, amongst the many essential components of shared decision-making is an understanding of the patient's knowledge. Charles and colleagues comment that patients come to each medical encounter "with their own beliefs, values, fears, illness experiences and, increasingly, information about various treatment options" (Charles, Gafni, and Whelan 1999).Therefore, it is essential to understand a patient's sources of information, misinformation, gaps in knowledge, and desire for additional information.

Patients use a variety of sources for information to inform their clinical encounters with physicians, but increasingly they are searching the web for medical information. Since the turn of the century, there has been an explosion of websites intended to provide medically related patient information. Between 1998 and 2010, the number of Americans using the Internet to seek health information increased from 60 to 175 million (Harris 2010) and recent surveys demonstrate that up to 88% of adult Americans search online for health information (Harris 2012; Ahmad et al. 2006). Patients seek information for a multitude of reasons: to better inform themselves about their disease and treatment options; to aid in decision making when they are dissatisfied with the information provided to them by health professionals; and to reassure themselves that they have all necessary information (Diaz et al. 2002; Dickerson et al. 2011; McMullan 2006).

While patients assert that the Internet empowers them to make health care decisions, more than 70% of patients find the information presented on websites to be conflicting and 30% find it to be overwhelming and confusing (Eysenbach 2003). Evidence suggests that patients lack the knowledge and ability to critically evaluate the information they find on the web and even in cases when they have skills to evaluate information, they do not apply these skills (Gunther, Eysenbach and Köhler 2002). A considerable amount of web-based information is unfiltered and unedited and virtually anyone can construct a website and post patient materials (Silberg 1997). Bader and Braude comment that, unlike peer reviewed books and scholarly articles, "the Internet allows anyone to be an instantaneous publisher" (Bader and Braude 1998). As a result the information a patient reads may not be applicable to their disease, may be

inaccurate, or may be out of date. As patients increasingly search the web for health information, this information will comprise part of many patients' knowledge base. Thus, to engage in shared decision-making, an understanding of the quality of the Internet information being brought to the clinical encounter will be integral to the physician patient encounter. Some experts have asserted that physicians should add the question, "What Internet sites have you visited?" to their standard history taking (Bader and Braude 1998). However, to aid in effective shared decision-making, it is not enough to simply identify the resources patients are using. Rather, physicians must also be able to appraise the quality and content of the information in these resources and help the patient in understanding how these resources apply to their disease process.

If practicing physicians should be skilled in the interpretation and translation of medical information for patient care, these competencies must be defined and assessed in medical training programs. In Canada, the CanMEDS framework was adopted by the Royal College of Physicians and Surgeons of Canada (RCPSC) in 1996 (Frank et al. 1996). The CanMEDS framework formulates a set of essential physician competencies required for medical education and practice which include seven roles: Medical Expert, Communicator, Collaborator, Manager, Health Advocate, Scholar and Professional (Frank 2005). While no CanMEDS competency is specifically linked to patient education, components of Scholar and Communicator make reference to such competencies. As defined by the Scholar role, "physicians demonstrate a lifelong commitment to reflective learning, as well as the creation, dissemination, application and translation of medical knowledge". Key competencies, in the role of Scholar, include the ability of physicians to "accurately convey relevant information and explanations to

patients and families, colleagues and other professionals and to deliver information to a patient and family, colleagues and other professionals in a humane manner and in such a way that it is understandable, and encourages discussion and participation in decision making". Additionally, physicians must be able to "critically evaluate medical information and its sources, and apply this appropriately to practice decisions". As communicators, "physicians effectively facilitate the doctor-patient relationship and the dynamic exchanges that occur before, during, and after the medical encounter". Specific key competencies, in the role of Communicator, include the ability to "accurately convey relevant information and explanations to patients and families, colleagues and other professionals ". The College of Family Physicians of Canada has adopted a modified version of the CanMEDS competencies (the CanMEDS-FM framework) (Tannenbaum et al. 2011). Similar to the CanMEDS framework, the Scholar and Communicator CanMEDS-FM roles indicate that family physicians should "engage patients, families, and relevant health professionals in shared decision making to develop a plan of care" and "facilitate the education of patients, families, trainees, other health professional colleagues, and the public, as appropriate". The Accreditation Council on Graduate Medical Education (ACGME) has formulated a similar set of six core competencies that include Patient Care, Interpersonal and Communication Skills, Medical Knowledge, Practice-based Learning and Systems-based Practice. As with CanMEDS and CanMEDS-FM, aspects of patient education are threads amongst other competencies. With respect to ACGME, descriptions of the competencies of Practice-based Learning and of Interpersonal and Communication Skills make reference to patient education.

While postgraduate competency frameworks contain references to patient education, there is no discussion of specific competencies related to translation and appraisal of Internet-based resources. Authors of undergraduate medical education competency frameworks have acknowledged the need to educate medical students with respect to such competencies and have paid special attention to the use of the Internet as a source of medical information. The report of the AAMC Medical School Objectives Project (MSOP) states that educators must "facilitate student learning in information retrieval, including the identification and acquisition of documents from the web and in filtering, evaluating and reconciling this information" (McGowan, Passiment, and Hoffman 2007). The authors of the recent Future of Medical Education in Canada (FMEC) paper state that "based on rapid and evolving technological changes related to the way people communicate and learn there must be increased understanding and use of technology on the part of both faculty and learners"(Hodges et al. 2011).

There is a paucity of research in postgraduate training to determine whether competencies related to interpretation, appraisal and translation of web-based medical information for the purposes of patient care are being taught and assessed. However, there is evidence to suggest that in undergraduate medical education these competencies are not being achieved. Studies of undergraduate medical education have demonstrated discrepancies between medical students' self-assessed and actual competency in critically evaluating electronic medical resources. In one survey, more than 50% of medical students believed they were competent in critically evaluating electronic resources while their medical educators believed that only 20% were competent in this skill at graduation (Scott et al. 2000). Similar results were described in

the 2013 Association of American Medical Colleges (AAMC) graduating medical student questionnaire (AAMC 2010).

The limitations of physicians-in-training to evaluate web-based information persist into practice and ultimately effect patient care. There is evidence to suggest that many practicing physicians feel unprepared to deal with patients who bring Internet information to their consultation (Potts and Wyatt 2002; Dedding et al. 2011). Few physicians take the time to ask patients what information sources they have used and even fewer may recommend the Internet as an information source. In one study, while 60% of patients expected their physicians to recommend web-based information, only 3% of physicians recommended sources on the Internet for health information (Diaz et al. 2005). Some physicians report that the exercise of contextualizing and interpreting Internet information is time consuming and puts a burden on them (Ahmad et al. 2006). Physicians have uncertainty regarding the accuracy of information on websites, limited access to up to date resources and limited skill sets to interpret the quality of the information on the Internet. This situation can negatively impact the physician-patient relationship and the health care system. When physicians are faced with a bulk of information to interpret, visit length increases, unnecessary referrals to specialists are made and patients may be interpreted as "difficult" and discharged without a care plan (Ahmad et al. 2006). Even those who feel skilled in helping patients to interpret Internet-based information may not be as competent in this skill as they perceive.

There are several strategies proposed in the literature to help physicians to integrate patient knowledge of Internet-based resources into the clinical encounter. Physicians can guide patients to "approved sites", sites that reinforce the consultation

(Gerber and Eiser 2001; Hart, Henwood, and Wyatt 2004). This strategy could be termed, "the Internet prescription" (Gerber and Eiser 2001; López-Gómez et al. 2012). For some patients, being directed to trusted sources might be an adequate way to integrate the Internet in decision-making. However, some patients may express a greater interest in a shared model of decision-making and the physician should be responsive to this interest. For these patients, physicians might serve as "the processors of information rather than the providers of information" (Hart, Henwood, and Wyatt 2004). In this light, physicians could work with patients to interpret the information on the websites with respect to their disease and participate more equally in the decision-making process, an approach more consistent with shared-decision making principles.

The question arises, how can a physician evaluate the quality of websites used by their patients? A framework may be a useful starting point to help physicians to make preliminary judgments about the quality of web-based resources, guide patients to websites that are considered more applicable, accurate and comprehensive, and provide patients with evaluation parameters. Evaluation frameworks are widely used in medical practice. As an example, for several decades physicians have been taught skills in the critical appraisal of literature (Oxman, Sackett, and Guyatt 1993). Much of the skills of critical appraisal are nested in evidence based medicine which is designed to "provide clinicians with strategies and tools to interpret and integrate evidence from published research in their patient care" (Guyatt et al. 2000). Evidence based guidelines provide health care professionals with a framework to critically evaluate the quality of resources intended for use by health care professionals to aid clinical decision

making. In contrast to EBM, we are interested in a framework to evaluate the quality of resources used by *patients* to inform their understanding. While the principles of evidence based medicine can help provide guidance, there are criteria and approaches specific to the evaluation of patient related information sources (Coulter 1998).

Many early evaluation frameworks for patient education resources were meant to be applicable to printed patient-related materials, not necessarily provided on the web. However, with an increase in web-based patient information, there has been a push to develop tools to evaluate the quality of health related websites. While there are a multitude of tools available for the evaluation of web-based information, there is no single standardized and validated tool tailored to appraising Internet-based health-related information. Several authors have proposed essential components of rating tools, yet no single tool adequately encompasses all of these domains (Silberg 1997).

To summarize, to enable effective shared decision making of physicians with patients, we must prepare them to integrate the knowledge that patients bring to their interactions. As more patients seek web-based information, we need to provide physicians-in-training, and ultimately in practice, with the tools and expertise to interpret and integrate this information into shared decision models. While there is an expectation that medical school and residency programs train physicians to provide comprehensive patient education, there is evidence to suggest this patient education may not be taking place, especially with respect to web-based resources.

There have been some attempts to define these specific competencies and design programs to provide medical trainees with skills related to the interpretation of web-based information (McGowan and Berner 2004; McGowan et al. 1998). However,

there is a paucity of literature discussing best practices to provide instruction and assessment for these competencies. A possible starting point for a program of research designed to articulate best practices is development of a framework that can be used by physicians and patients to evaluate web-based resources.   Thus, for the purposes of this research, we will concentrate on development of a tool to aid in the evaluation of web-based resources. We propose to develop an evaluation tool based on currently available tools, using the best attributes of current tools and addressing recognized limitations of these tools. We will use the tool to evaluate a selection of currently available patient web-based resources for two specific disease sites. This approach will serve two complementary goals: 1) to examine the usability of the tool and 2) to allow us to concurrently refine/revise the tool. As a peripheral benefit, through the application of this tool to currently available web-based resources, we will obtain a biopsy of currently available patient information websites for two specific diseases. The results of this research will ultimately inform a larger program of research that will provide medical students and residents with the skills necessary to interpret web-based information and to collaborate with patients in navigating the Internet for the purposes of improving health care delivery.

II. PURPOSES OF THIS RESEARCH

The primary purpose of this research is to develop and assess the properties of a tool to aid in the evaluation of web-based patient information by health professionals. Through the application of this tool, a secondary outcome of this research will be an evaluation of the quality of currently available resources for two common cancer types, lung and skin cancers.

III. METHODS

To conduct this study we used a multi-phased approach. This approach included:

1. A literature review and tool design.

2. Iterative application and modification of the tool.

3. Evaluation of the tool and iterative design with repeated application and
    modification of the tool.

The following sections describe the methods in greater detail.

1.   Step 1: Literature Analysis and Tool Design

To develop an evaluation tool, a review of the literature was undertaken to
examine currently available tools. Search engines used included: PubMed, EMBASE,
Web of Science, ERIC, Pyscinfo and BEME. The initial search terms used included:
(quality or evaluation or assessment) and (information or education) and (Internet or
world wide web). Citations were reviewed for relevance and articles retrieved if they:

1. Described tools or instruments for the evaluation of web-based
    information.

2. Described strengths and limitations of current tools or described qualities
    of current evaluation tools.

The UIC and UBC library were searched for textbooks and book chapters specifically
describing the evaluation of patient information websites. A search of the Internet using
the meta-search engines, Yippy and Dogpile, and the search engines Google, Yahoo,
Lycos, Excite, and Infoseek, was undertaken to search for evaluation tools for web-

based information. A search of the grey literature included: a review of conference proceedings (e.g., Health Literacy Annual Research Conference, American Medical Informatics Association, World Congress on Social Media, Mobile Apps, and Internet/Web 2.0 in Health, Medicine, and Science) and websites of medical education accreditation bodies (e.g., RCPSC, ACGME, LCME).

Once the literature review was complete, papers were reviewed if they:

- Described a tool for the evaluation, or an approach to evaluation, of web-based patient education resources

- Described the strengths and limitations of currently available evaluation tools or approaches to evaluation of web-based resources

- Described the needs of patients, health care providers and/or the health care system with respect to evaluation of web-based patient education resources

A list of currently available tools and criteria for evaluation of websites was compiled. The tools and criteria were reviewed and compared to lists of criteria described in the literature congruent with patient needs and providing accepted judgments of quality. By examining the criteria, and currently available tools, and identifying overlaps, it was possible to merge multiple tools into one "meta-tool". Thus, the product of this review of the literature was the development of a tool based on the best available evidence.

2. **<u>Step 2: Iterative Application of the Tool Based on Design-Based Research</u>**

To evaluate and iteratively improve the tool, we used constructs from design-based research (Reeves, Herrington, and Oliver 2005; Dolmans and Tigelaar 2012). We used an iterative process to develop and modify an evaluation tool, while concurrently using the tool to systematically evaluate the quality of web-based patient resources. Consistent with design based research, we used "continuous cycles of design, evaluation and re-design" (DBRC 2003). The research, based on design-based research (Dolmans and Tigelaar 2012), essentially consisted of repetitive cycles of:

1. Analysis and Tool Design

2. Tool Application and Evaluation

3. Analysis of Tool and Redesign

A flowchart showing the design process used is shown in Figure 1.
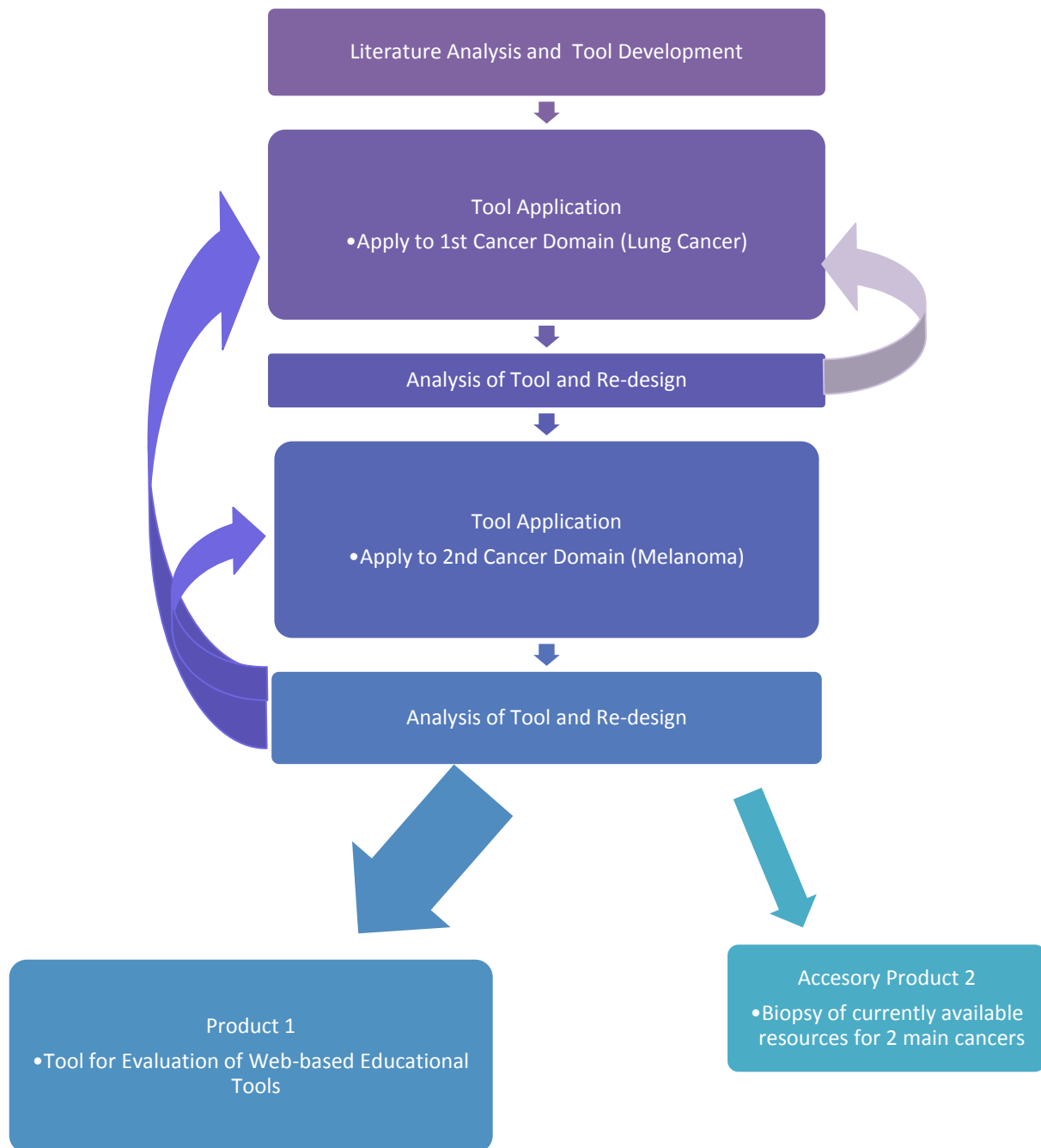
Figure 1: Flow chart for research design. The curved arrows represent re-analysis of websites with revised tool as required.

To elaborate on Figure 1 (above), an evaluation tool was developed based on a literature review. For the purposes of this study, we focused on oncology-related patient information websites and evaluated websites for two common cancers, lung and melanoma, in an iterative approach. In the first cycle, the tool was used to evaluate the quality of resources for one cancer domain, lung cancer. The tool was evaluated for inter-rater reliability and usability. Results of tool evaluation were used to modify and redesign the tool. To help to support generalizability, the tool was then applied in a second iteration and used to evaluate the quality of websites for a second cancer domain, melanoma/skin cancer. The tool was again evaluated for inter-rater reliability and usability. The tool was modified and re-designed, as needed. Significant changes were incorporated into a revised tool and the modified tool was used to re-evaluate the results from the first iteration i.e., re-evaluate lung cancer websites.

3.   Selection of Focus of Web-based Materials

We choose to apply the tool to oncology related websites. This was done for several reasons. First, the principal investigator on this project (P.I.) practices as a radiation oncologist. Therefore, this was an area of content expertise for the research team. Second, cancer is one of the most common health issues reviewed by patients on the Internet (Goto and Nagase 2012; Bylund et al. 2012). While lung and skin cancers are some of the most commonly searched cancers on the Internet, no studies had comprehensively evaluated the quality of patient education websites focused on these types of tumors (Bader, Theofanos, and Theofanos 2003). By using the tool to systematically evaluate the quality of oncology websites related to skin and lung cancer,

the products of our research would not only be used in tool development, but would also be a biopsy of currently available oncology patient resources for commonly searched cancers.

4.   Identification of Websites for Evaluation

Preliminary research demonstrated that a search for "melanoma and lung cancer" would return an extremely heterogeneous set of "hits". For the purposes of this study, we clearly defined the websites to evaluate as those intended to provide patient-oriented information relevant to each cancer type. A set of inclusion and exclusion criteria were formulated to identify the websites for evaluation.

Inclusion Criteria:
1. Websites intended for the purposes of patient education, providing general information related to the searched cancer.
2. Websites accessible without a subscription.

Exclusion Criteria:
1. Websites not intended for the purposes of general patient education.
   1.1. Sites exclusively dedicated to fundraising, pharmaceuticals, and advertising treatments, and not containing any specific cancer information for patients.
   1.2. Websites designed specifically for health professionals.
   1.3. Websites solely based on blogs, mailing lists or discussion boards.
   1.4. Decision tools.

2. Websites with no unique information, i.e., those merely providing links to:
   2.1. Other sites
   2.2. Other published materials (e.g., pdfs or journal articles)
   2.3. News articles
   2.4. Search engines or resource directories
And containing no specific patient information hosted by the site

3. "Dead" websites, not accessible by the URL provided by the search engine

Two meta-search engines and one single search engine were used to compile a list of the top 100 websites a patient would access when looking for information using

the search terms "lung cancer" and "melanoma". We used the search engine, Google, and the meta-search engines, Clusty/Yippy and Dogpile. The search terms were inputted into the three search engines. We recorded the first 200 "hits" for each search engine (600 in total) to ensure that after the application of the exclusion criteria that we would have enough hits to produce a list of 100 websites. The set of inclusion and exclusion criteria, listed above, were then applied. A list of 100 websites was compiled based on the relative rank order appearance of the site in the retrieved list from each engine. For example, when the site appeared on all three search engines in the order as #1 (Google), #8 (Clusty) and #10 (Dogpile), the site was assigned a numerical score of (1+8+10)/3=6.3. If a site did not appear in the list of the top 200, the site was assigned a relative number of 200+1 and this was used to calculate the order from most to least frequent appearance. The websites were then ordered from most to least frequent appearance, by number, to compile a list of 100 sites.

5. <u>Application of the Tool with Concurrent Evaluation and Modification</u>

Once the initial version of the tool was developed and the"100" sites were identified, the tool was applied.   The tool was used by two raters to establish usability and inter-rater reliability. A random list of 20 of the 100 websites was compiled. Two raters independently applied the tool to evaluate the websites. The inter-rater reliability for each item of the tool was compared, using the kappa statistic for the nominal ratings (e.g., yes/no), and the intraclass coefficient for continuous ratings (e.g., rating scales) (Viera and Garrett 2005; Cohen 1960; Rankin and Stokes 1998). For items on the tool having a reliability of <0.7, there was a review of the discrepancies in the ratings and a

discussion amongst raters on how to improve consistency by modifying the rating scale and operationalizing definitions (Sagaram et al. 2004). Following discussion, an additional 10 random websites were co-rated. The results were analyzed and, again, any items with a reliability of <0.7 were discussed to increase consistency in rating. Following evaluation of the initial websites, both raters discussed the definition of each item and general usability of the tool and made modifications to the tool based on these discussions. Data were collected on the modifications of the tool and any changes to the definitions for each of the quality parameters after operationalization were noted. If required, an additional 10 websites were co-rated and reliability for the items was reviewed as before. Once the ratings appeared consistent (with all items having a reliability >0.7) and the coding scale operationalized, the remaining websites (of the 100) were evaluated by a single rater.

The first iteration was conducted with lung cancer websites. The results of the evaluation of the 100 lung cancer websites were summarized using descriptive statistics. After analyzing the results for the lung cancer websites, the tool was used to evaluate skin cancer websites to assess the transferability of the tool to another domain. A similar process was undertaken in the next iteration to establish inter-rater reliability and to improve the reproducibility of ratings for the skin cancer sites. One hundred (100) skin cancer (melanoma) websites were evaluated using the tool. Consistent with the principles of design-based research outlined earlier, the "lessons learned" from each process of coding were used to continually modify and improve the tool. Major changes to the coding were used to re-analyze the previously rated data.

IV. RESULTS

Following from a multi-phased project, there were multiple results. They can be summarized as results of:

1. Literature Search for Criteria and Current Tools

2. Tool Development and Application

3. Analysis and Iterative Improvement of Tool

4. Evaluation of the Quality of Lung and Skin Cancer Websites

1. Results of Literature Review

The literature provided both an appreciation of potential criteria that could be included in development of a website evaluation tool and an understanding of the strengths and weaknesses of currently existing website evaluation tools. The findings of the review are detailed below and include:

a) The variety of current approaches and tools used to assess website quality

b) Criteria important to patients to make judgments about quality.

c) Additional criteria important to evaluate health related patient information.

i. Summary of Existing Tools and Approaches

The first finding from the literature review was the number of tools and variety of approaches that have been developed to assess patient education sites on the web. For example, one review paper on this topic identified 273 unique instruments examining

some aspect of health website quality (Bernstam et al. 2005). Many of these

instruments were developed independently and were presented only once in the

literature. Others were developed by well-established organizations and have gained

some level of credibility through wide distribution and repeated use.

The second finding from a review of the literature was the considerable

heterogeneity in the approaches used to make summary judgments about the quality of

web-based information. Of the 273 instruments identified in the Bernstam review, only

95 (35%) included checklist or scale type instruments usable by health professionals or

health care consumers. The remaining 178 (65%) "Instruments" were seals of approval

or quality labels, not necessarily intended for use by patients or health professionals. In

fact authors (Wilson 2002; Deshpande and Jadad 2009) identified as many as five

different approaches to quality rating for health websites (Jadad 2004; Charnock 1998;

Abbott 2000). A summary of these approaches, as well as examples from the literature,

are presented in Table I. Many of the approaches presented in the table were not

constructed for use by health care consumers or health professionals. For example, at

first glance, filters and quality labels did not readily look applicable to our tool

development as they did not contain typical checklists or scales. However, upon closer

examination, many of these approaches made summary judgments based on criteria

and contained information/criteria potentially useful for inclusion in our tool. Thus, for

the purposes of this project, we defined a patient education evaluation tool as an entity

consisting of a defined set of criteria intended to provide a rating or judgment of website

quality. We defined a criterion as an element on which a website can be easily

assessed with regard to congruence or non-congruence (Bernstam et al. 2005).

TABLE I: APPROACHES TO EVALUATION/MECHANISMS OF SUMMARY JUDGMENT OF THE QUALITY OF WEB-BASED PATIENT INFORMATION
[adapted from Wilson 2002; Deshpande and Jadad 2009]

Terms used in literature to define approach to evaluation	Description	Examples
User Guides	Checklists provided to consumers to aid in the review of information.	DISCERN(Charnock 1998) NetScoring("Net Scoring ®: Criteria to Assess the Quality of Health Internet Information" 2001)
Codes of Conduct	Quality criteria intended to guide web developers to produce sites adhering to standards (often with an ethical emphasis) agreed upon by a group.	AMA (Silberg 1997) Internet Health Coalition (Rippen and Risk 2000)
Self-Applied Quality Labels	A "seal of approval" added to websites conforming to set codes of conduct. Self-applied by the website administrator or developer and represents a commitment to set principles/criteria.	Health on the Net ("Health on the Net: HONcode Site Evaluation Form" 2014) Hi-Ethics (Kemper 2001)
Third Party Certification or Quality Labels	A "seal of approval", label or logo provided by a third party to "certify" compliance of the website to set criteria.	URAC ("URAC" 2014) Med Certain (G Eysenbach et al. 2000)
Filters	A group reviews websites, "tags" them based on preset criteria and then stores tags in database.	OMNI (Cooke and Gray 2002) *(note OMNI website disbanded and archived in 2011)*

The third finding from the literature review was the absence of a tool that was identified as a gold standard for website evaluation. Three extensive literature reviews conducted between 2002 and 2005 (Gagliardi and Jadad 2002; Gunther Eysenbach et al. 2002; Bernstam et al. 2005) identified several limitations and gaps in existing tools. First, across all literature reviews (Gagliardi and Jadad 2002; Gunther Eysenbach et al. 2002; Bernstam et al. 2005),relatively few tools could be identified that clearly outlined their criteria for evaluation. Bernstam reported that 80/273 (29%) of instruments clearly identified their criteria for evaluation. Gagliardi and Jadad, in their review, echoed this

finding, indicating that 19/98 (19%) of instruments explicitly delineated their criteria for evaluation. Second, authors of very few existing tools reported on the reliability or the validity of the measurements they provided. Gagliardi and Jadad, in their review, reported that no tool could be identified which reported a formal evaluation of either inter-observer reliability or "construct validity". The Eysenbach review identified 16/79 studies using evaluation tools that mentioned inter-observer reliability, and when evaluated, inter-rater reliability was low. Third, all reviews suggested that many current evaluation tools focused on the structure of the website (e.g., presence of functioning links, formatting), but failed to evaluate content with respect to authorship, accuracy, reliability and completeness. Table II summarizes the findings of the reviews.

TABLE II: SUMMARY OF PUBLISHED REVIEWS OF STUDIES EXAMINING QUALITY OF WEB-BASED PATIENT INFORMATION

Review/Authors	# of Instruments/Tools Identified	Summary of Review Findings
Gagliardi 2002 (Jadad update)	98 instruments (51 instruments were new compared to the initial review in 1998)	• 19/98 clearly identified criteria • 3/98 included authorship, attribution and disclosure as criteria • No tools appeared to be validated
Eysenbach 2002	79 studies/tools	• 6/79 tools identified design/structural criteria • 19/79 studies examined completeness and/or accuracy • 11/79 identified readability as a criterion • 31/79 studies used 2 raters and 20/79 attempted inter-rater measures, but all showed a high degree of inter-observer variability
Bernstam 2005	273 instruments	• 80/273 clearly identified the criteria for evaluation • 7/273 instruments (JAMA, MAYO, Publishing, WHO, Alexa, FDA, and Clark) consisted of objective criteria with a manageable number of rating categories (<10) • 1/273 (Mayo) had "acceptable" inter-observer reliability (kappa >0.6)

In summary, the many previous reviews of the literature in this area reveal a multitude of instruments available to make summary judgments about the quality of websites. While there are several tools with a checklist type format, there are other approaches with potentially valuable criteria used to make their summary judgments. There are recognized limitations of each of the current tools and approaches: few transparently identify their criteria for evaluation; many of the criteria evaluate site function as distinguished from content related criteria; and there is a lack of evidence with respect to inter-rater reliability.

Thus, while many approaches and many instruments exist to evaluate patient education websites, there is no clear gold standard, suggesting that the development of a new, more comprehensive and carefully evaluated tool is still needed. To this end, the following two sections review the literature for the purposes of identifying and organizing the criteria that should be used in the development of such a tool. Section 1b will focus on a description of the criteria from the perspectives of patients and health care consumers. Section 1c will focus on identifying other potential criteria not yet identified through the review of specific tools or the literature on patient perspectives.

ii.   Criteria Important to Patients/Health Care Consumers to Help Evaluate Web-based Information

Ultimately, the product of this research is intended to inform a research agenda related to the competency of physicians to provide patient education. Reviewing available tools from this lens, we reviewed the literature with respect to criteria useful for

patients/health care consumers in their search for websites for relevant disease specific information

Burkell et al. examined criteria used by "health care consumers" to make judgments regarding the quality of websites (Burkell 2004). They reviewed quality evaluation parameters from published studies and generated a list of 28 quality criteria (see Table III below). The authors categorized these criteria as information quality criteria (providing direct assessment of the quality of the information), proxy quality indicators (indirect indicators of quality e.g., correct grammar), and criteria related to interaction with the site (e.g., functioning hyperlinks). Research participants evaluated the list of 28 criteria based on perceived importance with respect to the expected contribution of each to a "seal of quality", and the ease of using each in evaluating a website. Respondents felt that the core aspects of 'information quality' (accuracy, currency, completeness and lack of bias), in addition to criteria specific to attribution, including authorship (e.g., author is knowledgeable, is identifiable and credentials are clear) and ownership (e.g., sponsorship clear, website is published by reputable organization, website includes disclaimer) would be the most useful to establish quality ratings. Interestingly, respondents felt most uncertain in their ability to evaluate website information using these criteria. Survey respondents felt most comfortable in their ability to use criteria related to site design (e.g., presence of a search function, lack of spelling errors), but rated these features as less important to determination of quality than the core aspects indicated above.

TABLE III: WEBSITE EVALUATION CRITERIA OF POTENTIAL IMPORTANCE TO PATIENTS
(BURKELL 2004)

	Quality Criteria
Information Quality Criteria	Accurate, reliable and error-free
	Unbiased
	Complete
	Up to date
Proxy Quality Criteria	The web page has no spelling, grammatical or typographical errors.
	Information provider is identified.
	Information provider can be contacted.
	Website is sponsored by a reputable organization.
	Link to sponsoring organization is provided.
	Information provider qualifications can be verified.
	Website identifies date of posting to the web and date of last update.
	Links are current.
	Website is accessible with basic software or links to plug-ins are provided.
	Website is easy to navigate.
Site (or interaction) Criteria	Feedback mechanism is available.
	Information is appropriate for people who are not medical professionals.
	A search function is available for the website.
	Topics covered by the website are identified (e.g., by site map).
	Website is stable and always accessible.
	Website is aesthetically pleasing.
	Information is provided free of cost.
	User support is available if required.
	Language used is basic and non-technical.
	Website includes a disclaimer describing the limitations of information. use.

Authors of additional studies have indicated that the qualities health consumers report that they look for to assess quality, are not always the same qualities that health care consumers actually use when observed in real time (Metzger 2007). Eysenbach and Kohler (2002) interviewed 22 health care consumers to identify the parameters they used to evaluate website quality. The majority of participants stated that parameters related to authorship and attribution (e.g., official websites and presence of citations), content (e.g., content appeared scientific or plausible), readability (e.g., understandable and professional writing) and site design (e.g., professional design) were criteria they

most often associated with quality. When the same group of participants was observed with respect to their web-searching strategies, however, few reviewed citations, authorship, site credentials or could identify the host/source of a website.

Fogg et al. 2003 reported one of the largest studies, with over 2600 consumers of web-based information. Analysis of these consumer responses demonstrated criteria, in four categories, that they used to evaluate site quality (Fogg et al. 2003). These categories included: site presentation (e.g., graphics, readability), site information (e.g., lack of bias, depth of information), motives of site sponsor (e.g., disclosure, presence of advertising) and source reputation (e.g., authorship, affiliations). Health care consumers, in their evaluation of patient education websites, placed a significant emphasis on websites containing information focused on a specific health care question and with a lack of advertising. Conversely, health care consumers placed little emphasis on the customer service of the website (e.g., ability to give feedback to a web master) to make judgments with respect to quality.

A review of the literature (next section) identifies five criteria felt important to make patient education website quality judgments, including accuracy, authority, objectivity, currency and coverage (Metzger 2007; Scholz-Crane 1998; Alexander and Tate 1999). Comparing this list to those in the above studies, it appears that patients do, in fact, make quality judgments, using these parameters, although there may be less of an emphasis on currency. Interestingly, while patients feel that these criteria help to make judgments about the quality of patient education websites, it appears that they lack the confidence to make these judgments independently and, in practice, may not use these evaluation parameters when actually viewing and evaluating websites.

iii. Additional Criteria Captured in the Literature Important to Evaluating Quality

In addition to research on criteria useful to patients/health care consumers to make quality judgments, there is a considerable amount of research focused on criteria felt to be indicative of "higher quality" websites. In reality, it is almost impossible to fully define "a higher quality website". In an ideal world, analogous to other areas in medicine, the best evaluation tool or criteria would identify a website that could improve health outcomes, improve patient knowledge or change patient behavior or a disease process (Gunther Eysenbach 2002). However, the treatment of any disease is extremely complex and a website, even if of high quality, is extremely unlikely to impact treatment. Even when a website improves knowledge of patients or health care providers, in reality most users access more than one site and thus it is difficult to determine the impact of one site alone.

Several studies have examined which evaluation criteria appear to predict for more accurate information. Technical details, including citation of references and an absence of financial interest (sponsorship), have been related to websites with more accurate content (Martin-Facklam et al. 2002; Martin-Facklam et al. 2003). Additional details, including the attribution of authors, credentials of authors and date of publication, may also be related to higher content quality (Martin-Facklam et al. 2003; Chen, Minkes, and Langer 2000).

While some criteria may not be related to predictions of accuracy, they are still important markers of quality. Examples of this include disclosure of sponsorship and privacy policies, which relate to ethical characteristics (Gunther Eysenbach 2002).

Such criteria can help to create a context for the user and may relate to judgments of quality. The sponsor of the site may also be important in evaluation of quality. Studies have shown that sites produced by academic institutions (e.g., universities) more often provide disclosure and attribution and are current (Chen, Minkes, and Langer 2000). Government and nonprofit sites also more frequently show the date of creation (Hoffman-Goetz and Clarke 2000) .

An additional body of literature has summarized five main criteria that are predictive for websites of higher quality. These criteria include authority, objectivity, currency, accuracy and coverage (Metzger 2007; Fritch and Cromwell 2001; Alexander and Tate 1999; Scholz-Crane 1998). Authority refers to authorship, including attribution, affiliations and credentials. Objectivity refers to disclosure of site purpose, lack of bias and sponsorship, while currency means that the information is up to date or has been recently updated. Accuracy and coverage refer to the content with respect to the depth of coverage and the congruence of this information with other information considered reliable.

In summary, there are a variety of criteria used by health care consumers to make judgments about the quality of websites. There is also a considerable amount of research focused on the impact of these patient criteria, and additional criteria, in making judgments about quality of patient education information on the web. An understanding of this body of knowledge was essential to move forward to instrument development.

2. **<u>Tool Development</u>**

The two primary findings of the literature review, above, were the identification of a variety of criteria important in the evaluation of quality, as well as a multitude of currently available tools. Moving forward to develop/select a tool for use in this study we:

a) summarized the criteria found in the literature identified in studies of health care consumers and other quality related research

b) examined currently available tools, with respect to our summary of relevant criteria and chose a tool for our study.

The following section describes this process.

i. **Summary of Criteria for Inclusion in an Evaluation Tool**

Taking into account our review of the literature, we were able to construct a summary table of criteria for potential inclusion in a tool for evaluation. Incorporating the research relevant to the perceived needs of patients, quality and accuracy, it appears that a robust evaluation tool would at a **minimum** contain criteria relevant to the following domains captured in Table IV below.

TABLE IV: SUMMARY OF RELEVANT CRITERIA BASED ON LITERATURE REVIEW

Type of Criteria	Criteria	Literature Supporting Inclusion
Technical Criteria	Site Design/Layout	(Burkell 2004; Gunther Eysenbach 2002)
Content Criteria	Readability	(Burkell 2004; Gunther Eysenbach 2002)
	Completeness/Scope of Coverage	(Burkell 2004; Gunther Eysenbach 2002; Scholz-Crane 1998)
	Accuracy	(Burkell 2004; Gunther Eysenbach 2002; Scholz-Crane 1998)
	Lack of Bias/Objective	(Burkell, 2004; Scholz-Crane, 1998)
	Currency	(Scholz-Crane 1998; Martin-Facklam et al. 2003; Chen, Minkes, and Langer 2000)
Source Criteria	Disclosure	(Silberg 1997; Gunther Eysenbach 2002)
	Authorship /Attribution	(Scholz-Crane 1998; Silberg 1997; Martin-Facklam et al. 2003; Chen, Minkes, and Langer 2000; Burkell 2004)
	Credentials	(Martin-Facklam et al. 2003; Chen, Minkes, and Langer 2000)
	Citations	(Martin-Facklam et al. 2002; Martin-Facklam et al. 2003)
	Site Provider/Affiliation Acknowledged /Sponsorship	(Burkell 2004; Chen, Minkes, and Langer 2000; Martin-Facklam et al. 2002; Gunther Eysenbach 2002)

ii. Analysis of Current Tools Available

Considering what appear to be relevant criteria for evaluating a tool (Table IV above), we examined currently available tools, for the purposes of finding tools that best exemplified achievement of quality related to these criteria amongst these tools. Based on the literature review, three tools appeared commonly in the literature that were supported by the best available research, with respect to evaluation by the criteria and

reported examination of inter-rater variation or made attempts at validation. These

three tools included HON, DISCERN, and JAMA tools ("Health on the Net: HONcode

Site Evaluation Form" 2014; Charnock 1998; Winker et al. 2000; Silberg 1997). The

tools in full are attached in Appendix A. Viewing the tools, it was evident that there were

both overlapping and unique criteria allowing for consideration of combining parameters

for the final tool for this study. Table V summarizes the rating criteria for each tool and

compares criteria (with relevant overlap) across columns.

TABLE V: SUMMARY OF RELEVANT CRITERIA FOR TO EACH HON, JAMA AND DISCERN TOOL

Classification of Criteria	Health on the Net (HON)	JAMA/Silberg	DISCERN
Disclosure	Website Disclosure	Disclosure	
	Advertising Policy		
	Transparency of Financial Sponsorship		
	Privacy Statements		
Completeness/Scope of Coverage			Content: Describes how treatment works. Describes benefits of treatment. Describes the risks of treatment Describes what would happen without treatment. Describes effect of treatment on quality of life. Provides support for shared decision making.
			Refers to uncertainty
			Explicit aims/objectives
Lack of Bias/objective			Balanced and unbiased
Currency		Currency	Date Explicit
Authorship/Attribution	Transparency of authorship	Authorship	
	Attribution of sources	Attribution	Source of info explicit
Citations	Citations/justification of claims		Citations for additional sources
Credentials	Author credentials present		
Affiliation	Website affiliation		

Using the three tools above as a starting point, we began to sketch the framework for the tool for use in this study. Reviewing the three tools above, and comparing them to the summary table of criteria (Table IV), areas not covered by any of these three tools included site design and layout, readability and accuracy.   As described in prior reviews and studies (Gunther Eysenbach 2002; Fogg et al. 2003; Metzger 2007; Fritch and Cromwell 2001; Alexander and Tate 1999; Scholz-Crane 1998), these criteria are felt by many to be integral to evaluation of website quality yet the latter, in particular, is often not included in current tools available. We deemed these as important additional criteria (site design/structure, readability and accuracy) and made a decision to include them in our final tool.

iii.   Initial Version of the Tool

Our initial tool included six main categories, incorporating criteria from the summary table, and features of at least three existing tools. We defined the broad categories included in our tool as:

1) Website affiliation

2) Accountability (authorship, attribution, disclosure and currency)

3) Interactivity

4) Structure and organization

5) Readability

6) Content quality (includes accuracy, coverage and objectivity)

For each of the categories, we used definitions/rating scales as described in relevant established tools (e.g., HON, DISCERN, AMA) or relevant studies (Eysenbach 2002;

Fogg et al. 2003; Metzger 2007; Fritch and Cromwell 2001; Alexander and Tate 1999;

Scholz-Crane 1998). Table XI (Appendix B) summarizes the initial tool and criteria,

based on the literature review and process described above.

3.   Analysis and Iterative Improvement of Tool

i.   First Iteration of Tool Application: Lung Cancer

Having developed the tool, we sought to evaluate and iteratively improve it. As a

first step in this process, we used the tool to evaluate the quality of 100 lung cancer

websites with cycles of application, evaluation and redesign (Figure 1).

ii.   Selection of 100 Lung Cancer Websites for Evaluation

The meta-search results, from both Clusty and Dogpile, returned 136,198 and

1,242 hits respectively and the Google search returned 21,500,000 hits. After examining

the first 200 hits for each, we eliminated 218 websites based on the exclusion criteria

and were left with 155 hits from Clusty, 107 from Dogpile and 120 from Google.

Appendix C-1 describes included and excluded websites. Results were rank ordered as

described in our methods section. A list of 100 websites was compiled (see Appendix

C-2).

iii. Application of the Tool to Lung Cancer Websites with Concurrent Evaluation

The initial version of the tool was applied to evaluate a random list of 20 of the 100 websites. Two raters (PI and a research assistant) independently applied the tool to evaluate the websites. The inter-rater reliability for each item is presented in Table VI.

TABLE VI: INTER-RATER RELIABILITY FOR THE FIRST 20 LUNG CANCER WEBSITES
(yellow indicates kappa <0.7)

Category	kappa/ICC*
Website Affiliations	1
Authorship Identification	0.5
Authorship Credentials	0.8
Attribution Sources Cited	1
Attribution Range of Sources	1
Attribution Resources Used	0.9
Disclosure	1
Currency date of creation specified	1
Currency last update	1
Currency Links Active	0.9
Interactivity	0.3
Site Organization	0.9
Flesch-Kincaid Grade Level Score *	0.7
Flesch-Kincaid Readability Index*	0.7
SMOG Index*	0.6
Accuracy	1
Coverage	0.7
Objectivity	0.8

Three items had a reliability of <0.7: author identification, interactivity and the readability index (SMOG). For these items, there was a review of the discrepancies in

the rating and a discussion amongst raters on how to improve consistency by modifying the rating scale and operationalizing definitions. A step-by-step process was undertaken to analyze each item and attention was paid to operationalizing the definitions and clarify the bases of rating for these criteria. Differences between raters were discussed and resolved by consensus, including reflection on the primary literature. Below is a description of the issues arising for each item.

a)   Operationalization of Authorship

Discussion revealed that raters had differing conceptualizations of the term author.   One researcher consistently included both reviewers and authors for the purposes of author identification, while the other researcher did not. On review of the primary literature that included authorship as a parameter for evaluation, only authors, and not reviewers, were used as the applicable metric for evaluation (Metzger 2007; Fritch and Cromwell 2001; Alexander and Tate 1999; Scholz-Crane 1998; Eysenbach and Köhler 2002; Silberg 1997; Martin-Facklam et al. 2003; Chen, Minkes, and Langer 2000; Burkell 2004). As such, for the purposes of operationalizing the definition, author was defined as identification of the primary author or group of authors, excluding reviewers.

b)   Operationalization of Interactivity

For the initial version of the tool, we used a modified version of the Abbott scale (Abbott 2000), to define interactivity as the degree to which the site engaged users. Specifically we asked:

Does the site engage the user? (e.g., Does the site provide any of the following: a within site search engine, audio or video support, discussion board or forums, workshops or modules, satisfaction or knowledge evaluation questionnaires for users, e-newsletter sign-up, member sign-up, or the possibility of sending queries to the webmaster or authors)

> None of the above components visible
>
> One interactive component
>
> Two or more interactive components

While many of the parameters appeared easy to evaluate (e.g., presence or absence of a within site search engine), others were more difficult to evaluate (e.g., presence of a function to send queries to authors). Upon review of discrepancies, it was felt that a broad question with respect to interactivity was likely not adequate. With the initial scoring system, two different websites could both be scored, "2" on interactivity, but one of them might only have two interactive components and another might have five. Reporting interactivity in aggregate provided no sense of which of the five interactive components were included or excluded, nor did it give a sense of where rater discrepancies were arising. As such, interactivity was re-structured to include the presence or absence of each of five components, evaluated individually. Interactivity was thus defined as:

Does the site engage the users based on the following categories?

1. Does the site offer a within-site search engine?

   No

   Yes

2. Does the site offer audio or video support?

   No

   Yes

3. Does the site offer patient discussion boards or forums?

   No

   Yes

4. Does the site allow for questions to be sent to the author or Webmaster with respect to information on the site?

   No

   Yes

5. Does the site offer educational support (e.g., workshops, modules, evaluation surveys)?

   No

   Yes

c)   **Operationalization of Readability**

Read-able.com was the online tool used to calculate readability. Read-able allows for direct input of web-based material (cut and paste) or can analyze a website, if given a URL. We had predetermined that direct input would likely yield more accurate

results, as the URL could potentially result in additional features of the website (e.g., text in advertisements) as being evaluated for readability. The ICC for the SMOG index was 0.6 and the Flesch-Kincaid grade level and Flesch-Kincaid index were 0.7. Upon discussion it was evident that the variability was arising, for the most part, from different sections being inputted for analysis. One rater would consistently "cut and paste" all written material from the website into the read-able tool for evaluation, while the other rater would cut and paste sections with respect to demographics, staging and treatment. To increase consistency, a decision was made to cut and paste "the Introduction", "Prevention", and "Treatment" sections of the site into the readability tool. These sections were chosen because much of the primary literature indicated that patients seek information with respect to prevention and treatment (Fogg et al. 2003). Also, many patients do not read more than the introduction; thus we felt that this approach was essential to evaluate the readability of the site. Of note, if a site only contained one or two of these three sections, the sections present would be inputted to the readability tool.

d)   Inter-rater Reliability Following Operationalization

Following discussion and operationalizing the categories/definitions, an additional 10 random websites were co-rated. The results were analyzed. The results of this coding are shown in Table VII. It appeared that operationalizing the definitions resulted in a satisfactory level of inter-rater reliability (Table VII). Both raters also remarked that

with the second round of coding, having discussed the categories in depth, rating was

significantly quicker and simpler.

TABLE VII: INTER-RATER RELIABILITY FOR THE SECOND SET OF 10 LUNG CANCER WEBSITES

Category	kappa/ICC*
Website Affiliations	1
Authorship Identification	0.9
Authorship Credentials	0.8
Attribution Sources Cited	1
Attribution Range of Sources	1
Attribution Resources Used	0.9
Disclosure	1
Currency date of creation specified	1
Currency last update	1
Currency Links Active	0.9
Interactivity	
Presence of Within Site Search Engine	0.9
Queries to Web-master or Author	0.8
Presence of Discussion Boards	0.9
Audio/Visual Support	0.8
Educational Support	0.8
Site Organization	0.9
Flesch-Kincaid Grade Level Score *	0.9
Flesch-Kincaid Readability Index*	0.9
SMOG Index*	0.8
Accuracy	1
Coverage	0.7
Objectivity	0.8

iv.   **Results of the Analysis of Lung Cancer Websites**

Once the ratings appeared consistent (with all items having a reliability >0.7) and the coding scale was operationalized, the remaining websites (70 of the 100) were rated for quality by a single rater.   As mentioned previously, a secondary outcome of this research was a "biopsy" of the currently available websites for common cancers.

Analyzing 100 websites, using the tool, provided a rich description of the resources available to lung cancer patients.   The full results of the analysis are shown in Appendix D-1. In brief, the data can be summarized as follows. The most frequent administrators of lung cancer patient websites were commercial (45%) and non-profit organizations (36%). Although most websites declared authorship (93%), less than half (46%) cited author credentials or affiliations. Forty-two percent (42%) of websites failed to identify a date of creation or modification. For websites stating a creation or modification date, only 51% had updated their information within 2 years. A slim majority of websites (54%) use three or more interactive components (defined as site search engine, queries webmaster, discussion boards, audiovisual and educational support). The most common interactive components were inquiries to a web-master or author (93%) and a within-site search engine (73%). One-quarter (26%) of sites had a discussion board or forum, while 31% offered audiovisual and 30% educational support. A readability assessment revealed that 67% of websites required an average education of between grades 9 and 12 and over a quarter of websites (26%) required, for readability, some post-secondary education. The majority of websites provided basic information, which was mostly accurate (80%) and sufficiently addressed the topic of lung cancer (91%). In summary, while there were strengths identified in the lung cancer

patient websites (adequate coverage and accuracy) there were some weaknesses, with information being presented at a reading level higher than the average patient and many websites presenting information which had not been updated since their creation.

4.   <u>**Analysis and Iterative Improvement of Tool with Application to Second Domain**</u>

i.   **Second Iteration of Tool Application: Melanoma**

Consistent with the design-based research basis of development of the tool, we applied the tool to evaluate websites for a second cancer domain, melanoma, to continue the process of application, evaluation and redesign (Figure 1). For the second iteration, we evaluated the quality of 100 melanoma websites.

ii.   **Selection of 100 Melanoma websites for Evaluation**

For the purposes of the melanoma search, we used the meta-search engine Yippy instead of Clusty, because Clusty's technology and search strategy was purchased by Yippy. The meta-search results from both Yippy and Dogpile, returned 687 and 392 hits respectively and the Google search returned 5,765,000 hits. We recorded the first 200 hits for each and we applied the inclusion and exclusion criteria. Results were rank ordered as previously discussed. A list of 100 websites was compiled. See Appendix C-3.

iii.   Application of the Tool to Melanoma Websites with Concurrent Evaluation

a)   Review of the Tool Prior to Application

For the purposes of evaluation of the melanoma websites, a new research assistant was recruited. This change was felt to be beneficial as this allowed the tool to be "tested" by a new rater in addition to the P.I. From a qualitative perspective, following the first application of the tool to lung cancer sites, both the P.I. and the prior summer student had agreed that a discussion to operationalize the definitions had been key to improving consistency of ratings. As such, prior to applying the tool to evaluate the melanoma sites, the melanoma research assistant and the P.I. reviewed the tool item by item to clarify the intent of each category, or ratings, and elaborate on the definitions as needed.

As the raters reviewed the tool, it was evident that minor modifications would help to clarify the definitions for three categories.

b)   Operationalization of Authorship

With respect to authorship the initial versions of the tool inquired:

Is the author/ institution and their affiliations clearly identified?

No

Yes

Upon review of websites, it was clear that authorship may be clarified in the absence of affiliation and vice versa. As such, it was decided to separate these two questions as follows:

1. Is the author/ institution clearly identified?

No

Yes

2. Is the author's affiliation clearly identified?

No

Yes

c)   Operationalization of Currency

In the case of currency the initial versions of the tool had inquired:

1. Has the date of creation and modification of the site been specified?

2. How current is the last update to the site (from date site is being assessed)?

Over four years ago

Between two-four years ago

Less than two years ago

For many sites the date of creation was different from the date of modification. Understandably, a creation date could be several years in the past; yet the modification date/date of last edit might be much more recent. Both the PI and the research assistant felt that it was important to identify sites that appeared to continually review

and modify the contents. Hence, prior to proceeding, the currency questions were modified to:

1. Is the date of creation (copyright date) of the site specified?

   No

   Yes

2. Is the date of modification clearly identified?

   No

   Yes

The third component of currency was kept the same.

3. How current is the last update to the site (from date site is being assessed)?

   Over four years ago

   Between two-four years ago

   Less than two year ago

d)   Operationalization of Active Links

Aside from currency of the websites, additional clarification was felt necessary to clarify the evaluation of active links. The initial version of the tool had inquired:

1. Are the links cited still accessible (check three random links)?

   No links provided

   At least one link is inaccessible

   All three randomly selected links are accessible

Both raters felt that it was important to identify both the number of links and the accessibility of the links and supported separating the questions. As such, the questions were modified to:

1. How many external links are provided?

    No links provided

    One link provided

    Two or more links provided

2. Are the external links (not advertising) provided functional (check up to five links in the order that they appear)?

    No links provided or none accessible

    Less than 50% of links are accessible

    Fifty percent (50%) or greater links are accessible

The updated tool to be used for rating the melanoma websites is seen in Table XII (Appendix B).

e)   Inter-rater Reliability Following Operationalization (first iteration melanoma)

The updated version of the tool (including the modifications to interactivity carried forward from the lung cancer website evaluation cycle and the modifications made prior to application of the melanoma website evaluation cycle) was applied to a random list of 20 of the 100 melanoma websites. Two raters (PI and a summer student) independently applied the tool to evaluate the websites. The results of the initial inter-rater reliability are seen in Table VIII below.

TABLE VIII: INTER-RATER RELIABILITY FOR THE FIRST 20 MELANOMA WEBSITES

Category	kappa/ICC*
Website Affiliations	1
Authorship Identification	0.9
Authorship Credentials	0.9
Attribution Sources Cited	0.9
Attribution Range of Sources	1
Attribution Resources Used	1
Disclosure	0.8
Currency date of creation specified	0.8
Currency date of modification	1
Currency last update	0.9
Link Number Active	1
Links Accessible	1
Interactivity	
Presence of Within Site Search Engine	0.9
Queries to Web-master or Author	1
Presence of Discussion Boards	0.9
Audio/Visual Support	1
Educational Support	1
Site Organization	0.8
Flesch-Kincaid Grade Level Score *	1
Flesch-Kincaid Readability Index*	1
SMOG Index*	0.9
Accuracy	0.8
Coverage	0.6
Objectivity	1

Congruent with the first application of the tool to evaluate the lung cancer

websites, for items having a reliability of <0.7, there was a review of the discrepancies in

ratings and a discussion between raters on how to improve consistency by modifying

the rating scale and operationalizing definitions. In the case of application to melanoma

sites, coverage appeared to have the greatest discrepancies in ratings with a kappa

<0.7 (kappa=0.6). A more detailed review of the kappa values from the first application

of the tool to evaluate the lung cancer data also revealed that this category may have

greater discrepancies in ratings and the kappa was 0.7 (Table VI and VII). As such, the definition of coverage was analyzed and the definition was redefined.

f)   Operationalization of the Definition of Coverage

For evaluating coverage, the question was initially phrased:

> How comprehensive is the information provided (e.g., is there information on definition, incidence/ prevalence, etiology/ risk factors, screening/prevention, prognosis and treatment)?
>
>> Not addressed (none of the above topics is covered)
>>
>> Minimally addressed (one-two of the above topics are covered)
>>
>> Sufficiently addressed (three -five of the above topics are covered)

The raters discussed the purpose of all subheadings (i.e., definition, incidence, etiology, prevention/screening, prognosis and treatment). A review of studies (Black and Penson 2006; Bichakjian et al. 2002) and existing tools (DISCERN) (Charnock 1998) demonstrated that those that had evaluated coverage had included similar categories. These categories were congruent with information presented on patient websites commonly thought to be of higher quality (UptoDate, NCCN patient guidelines). Also, several studies of patients' needs (Nguyen and Ingledew 2013; Rozmovits and Ziebland 2004; Cho et al. 2011) had demonstrated that patients seek information with respect to all of these categories. As such, the raters agreed that these subheadings would be kept.

There was consensus between the raters that the most consistent rating for this category would likely come from separating each of these topics. They felt that this would also provide a richer description of the available information and highlight potential gaps in the information online (e.g., Was there a paucity of information about risk factors or treatment by stage?). It was noted that the adapted questions could be altered to rate websites for non-malignancy with small changes to the wording.

The category of Coverage was thus changed to review coverage with respect to each topic.

How comprehensive is the information provided:

Is "the cancer" (i.e. lung cancer, melanoma) clearly defined?

No

Yes

Are current figures provided regarding the annual incidence or overall prevalence of "the cancer" (i.e., lung cancer, melanoma)?

No

Yes

Is the etiology of "the cancer" (i.e., lung cancer, melanoma) or its risk factors clearly identified?

No

Yes

Are prevention strategies for "the cancer" (i.e., lung cancer, melanoma) clearly

identified?

     No

     Yes

Are treatment strategies for each stage clearly described?

     No

     Yes

Is the prognosis for each stage clearly described?

     No

     Yes

The tool used for analyzing the remaining melanoma websites (Version 3.0) is

presented in Table XIII (Appendix B).

g)   **Inter-rater Reliability Following Operationalization (Additional coding of 10 melanoma websites)**

Following discussion and operationalizing the categories of coverage, an

additional 10 random websites were co-rated. The results were analyzed. The results

of this coding are presented in Table IX.   Once again, operationalizing the definitions

resulted in increased inter-rater reliability, specifically for the area of coverage.

TABLE IX: INTER-RATER RELIABILITY FOR THE SECOND SET OF 10 MELANOMA WEBSITES

Category	kappa/ICC*
Website Affiliations	0.8
Authorship Identification	1
Authorship Credentials	1
Attribution Sources Cited	1
Attribution Range of Sources	1
Attribution Resources Used	1
Disclosure	1
Currency date of creation specified	0.7
Currency date of modification	1
Currency last update	1
Link Number Active	1
Links Accessible	1
Interactivity	
Presence of Within Site Search Engine	1
Queries to Web-master or Author	1
Presence of Discussion Boards	0.7
Audio/Visual Support	1
Educational Support	1
Site Organization	1
Flesch-Kincaid Grade Level Score *	0.9
Flesch-Kincaid Readability Index*	0.9
SMOG Index*	1
Accuracy	0.7
Coverage Definition	1
Coverage Incidence	0.9
Coverage Etiology	1
Coverage Prevention	1
Coverage Treatment	0.7
Coverage Prognosis	1
Objectivity	1

iv. Results of the Analysis of Melanoma Websites

With the revised definitions, the inter-rater reliability for each category was =/>0.7, and the remaining 70 websites for melanoma were rated and analyzed by a single rater. The results of this analysis are presented in Appendix D-2.

In brief, the data can be summarized as follows. The most frequent administrators of melanoma websites were commercial (48%) and non-profit organizations (29%). Only half (50%) of websites indicated authorship and half of these (51%) cited their credentials. While 81% of websites identified a date of creation, less than half (45%) indicated a modification or update of their information within the past 2 years. The vast majority of websites allowed for inquiries to a web-master or author (87%) and contained a within-site search engine (76%). Only 8% of websites offered educational support. A readability assessment revealed that most websites required a grade 10 education for understandability and 10% required grade 12 or higher education. The majority of websites provided information which was mostly accurate (86%). Almost all websites provided a definition (93%) and description of the epidemiology (91%) of melanoma. Few websites described stage specific treatment (36%) or prognosis (15%). In summary, while there were strengths in the melanoma patient websites (adequate coverage with respect to etiology and accurate information), there were some gaps. There was a paucity of information with respect to prognosis or treatment. Many websites had not been updated within two years of the evaluation assessment and much of the information presented was at a readability level greater than the reading ability of the average patient.

5.   <u>**Application of Modified Tool to Lung Cancer Websites**</u>

Consistent with the principle of design-based research, following modifications to the tool, we had a priori decided to re-analyze the lung cancer websites with any changes to coding. As such, we re-evaluated the lung cancer websites with the revised definitions of:

1) Authorship

2) Currency

3) Links

4) Coverage

We revisited the previous 100 lung cancer websites and co-rated a random sample of 10 websites again to evaluate the inter-rater reliability when applied to the lung cancer domain for the revised categories. The results of this are seen in Table X.

TABLE X: REPEATED INTER-RATER RELIABILITY WITH A RANDOM SAMPLE OF 10 LUNG CANCER WEBSITES (new categories in italics)

Category	kappa/ICC*
Website Affiliations	1
Authorship Identification	0.9
Authorship Affiliation	1
Authorship Credentials	0.8
Attribution Sources Cited	1
Attribution Range of Sources	1
Attribution Resources Used	0.9
Disclosure	1
Currency date of creation specified	1
Currency date of modification	1
Currency last update	1
Currency Number Links	0.9
Currency Links Accessible	0.7
Interactivity	
Presence of Within Site Search Engine	0.9
Queries to Web-master or Author	0.8
Presence of Discussion Boards	0.9
Audio/Visual Support	0.8
Educational Support	0.8
Site Organization	0.9
Flesch-Kincaid Grade Level Score *	0.9
Flesch-Kincaid Readability Index*	0.9
SMOG Index*	0.8
Accuracy	1
Coverage Definition	1
Coverage Incidence	0.7
Coverage Etiology	1
Coverage Prevention	0.8
Coverage Treatment	1
Coverage Prognosis	1
Objectivity	0.8

With the revised definitions there was good inter-rater reliability and no categories were <0.7. This finding implied, in part, transferability of the revised tool across different domains. The remaining 90 lung cancer websites were then re-evaluated with the new categories. Of note, four previous links were now "broken" or no longer available. As a result, there were 96 websites accessible on which to apply the modified definition of coverage, currency, links and authorship.

The results of the revised analysis are presented in appendix D-3. The results of the "quality of the lung cancer" websites did not change significantly with these modifications, but the description of the available resources was more robust. More specifically, the revised tool provided a richer description of the coverage of lung cancer topics, revealing that less than half of the websites covered the topics of incidence (40%) and prognosis (46%). Also, separating creation from modification date revealed that only 14% of websites indicated a creation date, while 54% indicated a modification date.

6.   <u>Summary of Final Tool with Modifications</u>

In summary, we have developed a tool to aid in the evaluation of web-based patient resources. We used an iterative process, based on the principles of design-based research. The product of this process is a detailed tool for the evaluation of resources with a secondary product to provide a description of the current state of web-based oncology patient resources, for lung cancer and melanoma. The figure below (Figure 2)

depicts the design process and the changes integrated into the final tool (see Appendix

B, Table XIII).

Literature Analysis and Tool Development

Tool Application
•Apply to 1st Cancer Domain (Lung Cancer)

Modify: **Authorship Readability, Interactivity**

Proceed to rate remaining 80 (10+70) lung sites

Reanalyze with Modification to:
Authorship, Currency, Links, Coverage

Proceed to re-analyze 96 lung websites (4 links broken)

Analysis of Tool and Re-design

Tool Application
•Apply to 2nd Cancer Domain (Melanoma)

Modify: **Authorship, Currency, Links**

Proceed to co-rate remaining 20 melanoma sites

Modify: **Coverage**

Proceed to rate remaining 80 (10+70) melanoma sites

Analysis of Tool and Re-design

Product 1
•Tool for Evaluation of Web-based Educational Tools

Accesory Product 2
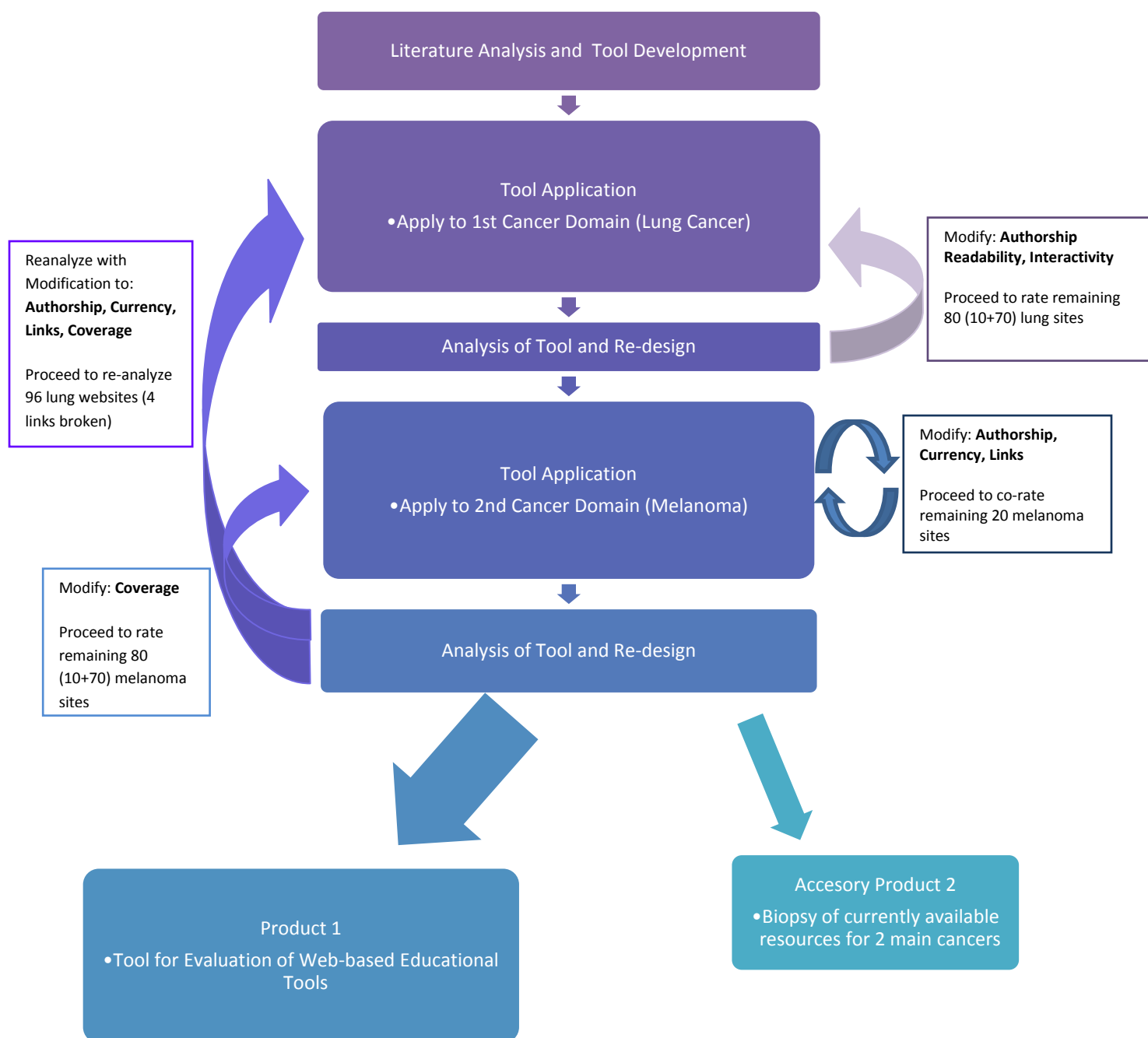•Biopsy of currently available resources for 2 main cancers

Figure 2: Flow chart for research design with modifications. The curved arrows represent re-analysis of websites with revised tool as required. Modifications made to the tool are indicated on the curved arrows.

V. DISCUSSION

We started this program of research by suggesting that both the models of shared decision-making between physicians and patients, and the increased access of patients to information (but not competence to assess that information), requires that physicians develop competencies in reviewing web-based information much as they have had to develop skills in EBM. While current competency frameworks for physicians (ACGME and CanMEDS) globally define or mention such competencies, there is a lack of a detailed description of such competencies. Thus, viewing these current competency frameworks (ACGME and CanMEDS), it appears that there is an opportunity for both original research and educational initiatives that seek to define the components of such competencies, the underlying frameworks for instruction and initiatives to improve the instruction and assessment of such competencies.

As a starting point for a program of research, we argued that it was necessary to develop a comprehensive framework for evaluating patient information websites that could serve as a basis for evidence based curricula in website evaluation. We used, as a starting point for such a framework, the development of a website evaluation tool that was grounded in criteria for evaluation viewed as important, based on a comprehensive review of the literature pertinent to such criteria and informed by well recognized (but acknowledged to be incomplete and imperfectly vetted) website evaluation tools. It was our hope, and expectation, that by developing such a tool and iteratively improving it through successive application/evaluation cycles, we would both create an evaluation

instrument that might serve as a gold standard and also refine the conceptual framework for website evaluation.

The resulting framework/tool from this study includes six dimensions:

1) Website affiliation

2) Accountability (authorship, attribution, disclosure and currency)

3) Interactivity

4) Structure and organization

5) Readability

6) Content quality (includes accuracy, coverage and objectivity).

Within each of these dimensions there is a set of subcategories that are operationalized, and can be used for evaluation of patient information websites, with relatively little training. A repeated criticism expressed in our review of the literature was that few existing tools had evidence of inter-rater reliability (Eysenbach 2002; Eysenbach et al. 2002). We thus undertook a process of design-based research to not only develop the tool, but to iteratively evaluate its usability and inter-rater reliability to inform continued improvements to the tool. The tool developed shows excellent inter-rater reliability at the level of individual dimensions, and through iterative testing; those dimensions have been increasingly specified and operationalized in ways that reflect definitions supported by the literature.

Although limited at this point to two iterative cycles, and focused, so far, exclusively on websites for patient education in lung cancer and melanoma, this program of research has shown promise in evolving related to our initial goals. Admittedly, the tool requires further evaluation in areas outside cancer, for usability and

applicability, as well as reliability. Further, additional steps likely need to be taken to ensure that other experts in the field have affirmed the validity and comprehensiveness of the dimensions and subcategories developed.

Through successive iterations, we produced a tool based on the best available criteria for evaluation, with a high level of reproducibility and one that provides a rich description of web-based resources for patients. In the process of tool development, it has become clear that while this is likely a valid and reproducible tool, it may be time consuming for a physician or a patient to use the tool to evaluate every website and it may not be feasible for the typical physician to use in daily practice. However, our goal was not necessarily to create a "daily use" tool, but rather to use the tool development and application to create a theory- and evidence-informed framework that health care professionals could use to aid in the interpretation of web-based health care information for patients. In this sense the full tool may serve as a guide to medical professionals, to highlight categories useful in making quality judgments. Similar to the scaffolding provided by Evidence Based Medicine Frameworks, with repeated practice of the application of the website evaluation skills, with time the practitioner may become more efficient and effective in appraisal. As such, the research herein is a good starting place for education of medical students and/or residents, even if the full application of the tool is not feasible on a daily basis in practice. As an example, the principles of the tool could be incorporated into workshops or online learning modules that could be used in training programs.

Aside from just providing a framework for physicians to evaluate web-based patient education resources, the complete tool developed in this study may be useful to

patients and health care providers in specific settings. A large body of research has

investigated how patients integrate information, including web-based resources, into

decision-making (Metzger 2007). It appears that the level of attention a patient pays to

evaluating quality of web-based resources, or the amount of time one will allow for this

task, is dependent on the importance of the information. For some patients the

consequences of accuracy of the information may be more important than for others,

and a more detailed and comprehensive review of a website, with a validated evaluation

tool may be appropriate. At other times, a more cursory view of website quality is likely

appropriate. Fritch and Cromwell comment,

> "sometimes the significance of the information under scrutiny does not warrant
> extensive research and analysis, while in other instances extensive research and
> analysis may be crucial; it ultimately depends upon the purpose and intent of the
> user of the information" (p 251) (Fritch and Cromwell 2001)

As such, there may be times when a very detailed review of web-based resources may

be needed for patients and the detailed evaluation tool developed in this study may

serve as a resource for patients and health care providers to aid in their in-depth

evaluation of the quality of web-based information. Similarly, as in this study the tool

can be used in health care research to make detailed analysis of the quality of current

resources, providing detailed and rich descriptions of web-sites.

While not the primary focus of this research, a peripheral product of this research

was a detailed evaluation of the quality of currently available web-based patient

resources with respect to lung cancer and melanoma. There were some notable

strengths and weaknesses. Across both lung cancer and melanoma websites, almost

all disclosed ownership, provided some level of interactivity, were mostly accurate and contained information with respect to a definition of the cancer and prevention. Of concern, many websites for both lung cancer and melanoma patients required a grade 10 education for comprehension, which may be markedly above the comprehension level of many patients. With respect to coverage, few websites included information on prognosis for either cancer. This is a concern because done by our research group have suggested that prognosis is one of the most commonly sought topics for patients (Hamilton et al. 2014)(Nguyen and Ingledew 2013). Less than 50% of websites for either cancer had recently been updated. These results not only highlight some specific areas for improvement in patient related websites, but may also help physicians to tailor patient conversations to provide information to address the gaps in the web-based resources.

In summary, this research is intended to inform a larger program of research that can provide medical students and residents with the skills necessary to interpret web-based information and to collaborate with patients in navigating the Internet for the purposes of improving health care delivery. As a starting point, we have identified the need to develop a framework for evaluating websites and in this study we have developed and evaluated a website evaluation assessment tool to highlight criteria and categories that may be useful for these purposes. In the end, the Internet is here to stay and we must examine ways to ensure that our physicians in training have the tools to comprehensively evaluate the web-based resources patients are using and integrate this into shared decision making.

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<u>APPENDIX A: TOOLS INTEGRTED FOR USE IN THIS STUDY</u>

The three tools used for inclusion included the HON, DISCERN, and AMA tools.

Links to the tools/or tools themselves (JAMA) are as follows:

HON: ("Health on the Net: HONcode Site Evaluation Form" 2014)

http://www.hon.ch/cgi-

bin/HONcode/Inscription/site_evaluation.pl?language=en&userCategory=individuals

(Accessed March, 2014)

DISCERN: (Charnock 1998)

http://www.discern.org.uk/discern.pdf

(Accessed March, 2014)

JAMA benchmarks: (Silberg 1997)

1. Authorship: Authors and contributors, their affiliations, and relevant credentials should be provided.
2. Attribution: References and sources for all content should be listed clearly, and all relevant copyright information included.
3. Disclosure: Web site "ownership" should be prominently and fully disclosed, as should any sponsorship, advertising, underwriting, commercial funding arrangements or support or potential conflicts of interest. This includes arrangements in which links to other sites are posted as a result of financial considerations. Similar standards should hold in discussion forums.
4. Currency: Dates that content was posted and updated should be indicated.

APPENDIX B: WEBSITE ASSESSMENT TOOLS (VERSIONS 1.0, 2.0 AND 3.0)

TABLE XI: WEBSITE ASSESSMENT TOOL VERSION 1.0 – CATEGORIES, SUBCATEGORIES AND SPECIFIC QUESTIONS AND RESPONSE CHOICES

Categories	Subcategories	Questions	Answer choices
Website Affiliation		1) What is the URL address? 2) Is the website administered by a commercial, university or non-profit organization?	• .com, .org, .ca
Accountability	Authorship	1) Is the author/ institution and their affiliations clearly identified?	• Yes • No
		2) Are the authors' credentials clearly indicated?	• Yes • No
	Attribution	1) Are sources of published information cited at the end or in the body of the document?	• Yes • No
		2) Is there a range of sources of information used in the website?	• Less than three cited • Three or more sources
		3) Are the resources used to compile the website reliable (i.e., do the authors use journal articles, peer-reviewed sites like UpToDate or e-Medicine, academic or government sites, textbooks)?	• No reliable sources used • One reliable sources used • Two or more reliable sources used
	Disclosure	1) Are ownership of the site, sponsoring and/or advertising disclosed?	• Yes • No
	Currency	Has the date of creation and modification of the site been specified?	• Yes • No
		How current is the last update to the site (from date site is being assessed)?	• Over four years ago • Between two-four years ago • Less than two year ago
		Are the links cited still accessible (check three random links)?	• No links provided • At least one link is inaccessible • All three random links are accessible
Interactivity		Does the site engage the users (e.g., Does the site provide any of the following: a within site search engine, audio or video support, discussion board or forums, workshops or modules, satisfaction or knowledge evaluation questionnaires for users, e-newsletter sign-up, member sign-up, or the possibility of sending queries to the webmaster or authors)?	• None of the above • One interactive component • Two or more interactive components

APPENDIX B: WEBSITE ASSESSMENT TOOLS (VERSIONS 1.0, 2.0 AND 3.0)

Categories	Subcategories	Questions	Answer choices
Structure & Organization		How is the information structured (e.g., Are any of the following structural tools used: headings, subheadings, diagrams/ pictures/ tables, hyperlinks, and absence of advertising)?	• None • Yes (give 1 point each for use of any of the listed structural tools)
Readability		1) Flesch-Kincaid Grade Level Score	• Grade level (1-19+)
		2) Flesch-Kincaid Readability Index	• 0 – 100 (A higher score reflects higher legibility [i.e. a greater reading ease])
		3) SMOG Index	• Grade level (1-19+)
		4) Average grade level	• Grade level (1- 19)
		5) Age easily understood	• Years
Content Quality	Accuracy	Is there conflicting information provided when compared to other reliable sources?	• Mostly not accurate • Mostly accurate • Completely accurate
	Coverage	How comprehensive is the information provided (e.g., Is there information on definition, incidence/ prevalence, etiology/ risk factors, screening, diagnosis, prognosis and treatment)?	• Not addressed (none of these topics are covered) • Minimally addressed (1-2 of these topics are covered) • Sufficiently addressed (3-5 of these topics are covered)
	Objectivity	Is there bias or opinion expressed when a writer interprets or analyzes facts (e.g., is there use of viewpoints or persuasive language)?	• Yes • No

APPENDIX B: WEBSITE ASSESSMENT TOOLS (VERSIONS 1.0, 2.0 AND 3.0)

TABLE XII: WEBSITE ASSESSMENT TOOL VERSION 2.0 – CATEGORIES, SUBCATEGORIES AND SPECIFIC QUESTIONS AND RESPONSE CHOICES (MODIFICATIONS IN BLUE FROM VERSION 1.0)

Categories	Subcategories	Questions	Answer choices
Website Affiliation		What is the URL address?	.com, .org, .ca
		Is the website administered by a commercial, university or non-profit organization?	
Accountability	Authorship	Is the author/ institution clearly identified?	Yes No
		Is the author's affiliation clearly identified?	Yes No
		Are the authors' credentials clearly indicated?	Yes No
	Attribution	Are sources of published information cited at the end or in the body of the document?	Yes No
		Is there a range of sources of information used to compile the website?	Less than three sources cited Three or more sources
		Are the resources used to compile the website reliable? (e.g., Do the authors use journal articles, peer-reviewed sites like UpToDate or e-Medicine, academic or government sites, textbooks)	No reliable sources used One reliable source used Two or more reliable sources used
	Disclosure	Are ownership of the site, sponsoring and/or advertising disclosed?	Yes No
	Currency	Is the date of creation (copyright date) specified?	Yes No
		Is the date of modification of the site	Yes

APPENDIX B: WEBSITE ASSESSMENT TOOLS (VERSIONS 1.0, 2.0 AND 3.0)

Categories	Subcategories	Questions	Answer choices
		specified?	No
		How current is the last update to the site (from date site is being assessed)?	Over four years ago Between two-four years ago Less than two years ago
		How many external links are provided?	No links provided One link provided Two or more links provided
	Links	Are the external links (not advertising) provided functional (check up to five links in the order that they appear)?	No links provided or none accessible Less than 50% of links are accessible 50% or greater of links are accessible
Interactivity		Does the site offer a within-site search engine?	Yes No
		Does the site offer audio or video support?	Yes No
		Does the site offer patient discussion boards or forums?	Yes No
		Does the site allow questions to be sent to the author or webmaster with respect to information on the site?	Yes No
		Does the site offer educational support (e.g., workshops, modules, evaluation surveys)?	Yes No
Structure & Organization		How is the information structured (e.g., Are any of the following structural tools used: headings, subheadings, diagrams/ pictures/ tables, hyperlinks, and absence of	None

APPENDIX B: WEBSITE ASSESSMENT TOOLS (VERSIONS 1.0, 2.0 AND 3.0)

Categories	Subcategories	Questions	Answer choices
		advertising)?	Yes (give one point each for use of any of the listed structural tools)
Readability	Readability: evaluated on the basis of "Introduction", "Prevention", "Treatment" sections of the site	1) Flesch-Kincaid Grade Level Score	Grade level (1-19+)
		2) Flesch-Kincaid Readability Index	0 – 100 (*A higher score reflects higher legibility [i.e. a greater reading ease]*)
		3) SMOG Index	Grade level (1-19+)
		4) Average grade level	Grade level (1- 19)
		5) Age easily understood	Years
Content Quality	Accuracy	Is there conflicting information provided when compared to other reliable sources?	Mostly not accurate Mostly accurate Completely accurate
	Coverage	How comprehensive is the cancer information provided? (e.g., Is there information on definition, incidence/ prevalence, etiology/ risk factors, screening/diagnosis, prognosis and treatment)	Not addressed (none of these topics are covered) Minimally addressed (one-two of these topics are covered) Sufficiently addressed (three-five of these topics are covered)
	Objectivity	Is there bias or opinion expressed when a writer interprets or analyzes facts (e.g., is there use of viewpoints or persuasive language)?	Yes No

APPENDIX B: WEBSITE ASSESSMENT TOOLS (VERSIONS 1.0, 2.0 AND 3.0)

TABLE XIII: FINAL WEBSITE ASSESSMENT TOOL VERSION 3.0 – CATEGORIES, SUBCATEGORIES AND SPECIFIC QUESTIONS AND RESPONSE CHOICES (MODIFICATIONS IN BLUE FROM VERSION 1.0)

Categories	Subcategories	Questions	Answer choices
Website Affiliation		What is the URL address?	.com, .org, .ca
		Is the website administered by a commercial, university or non-profit organization?	
Accountability	Authorship	Is the author/ institution clearly identified?	Yes No
		Is the author's affiliation clearly identified?	Yes No
		Are the authors' credentials clearly indicated?	Yes No
	Attribution	Are sources of published information cited at the end or in the body of the document?	Yes No
		Is there a range of sources of information used to compile the website?	Less than three sources cited Three or more sources
		Are the resources used to compile the publication reliable (e.g., Do the authors use journal articles, peer-reviewed sites like UpToDate or e-Medicine, academic or government sites, textbooks)?	No reliable sources used One reliable sources used Two or more reliable sources used
	Disclosure	Are ownership of the site, sponsoring and/or advertising disclosed?	Yes No
	Currency	Is the date of creation (copyright date) of the site specified?	Yes

APPENDIX B: WEBSITE ASSESSMENT TOOLS (VERSIONS 1.0, 2.0 AND 3.0)

Categories	Subcategories	Questions	Answer choices
			No
		Is the date of modification of the site specified?	Yes No
		How current is the last update to the site (from date site is being assessed)?	Over four years ago Between two-four years ago Less than two years ago
	Links	How many external links are provided?	No links provided One link provided Two or more links provided
		Are the external links (not advertising) provided functional (check up five links in the order that they appear)?	No links provided or none accessible Less than 50% of links are inaccessible Fifty percent (50%) or greater of links are accessible
Interactivity		Does the site offer a within-site search engine?	Yes No
		Does the site offer audio or video support?	Yes No
		Does the site offer patient discussion boards or forums?	Yes No
		Does the site allow questions to be sent to the author or webmaster with respect to information on the site?	Yes No
		Does the site offer educational support (e.g., workshops, modules, evaluation surveys)?	Yes No

APPENDIX B: WEBSITE ASSESSMENT TOOLS (VERSIONS 1.0, 2.0 AND 3.0)

Categories	Subcategories	Questions	Answer choices
Structure & Organization		How is the information structured? (e.g., Are any of the following structural tools used: headings, subheadings, diagrams/ pictures/ tables, hyperlinks, and absence of advertising?)	None Yes (give one point each for use of any of the listed structural tools)
Readability	Readability: evaluated on the basis of "Introduction", "Prevention", "Treatment" sections of the site	1) Flesch-Kincaid Grade Level Score	Grade level (1-19+)
		2) Flesch-Kincaid Readability Index	0 – 100 (*A higher score reflects higher legibility [i.e. a greater reading ease]*)
		3) SMOG Index	Grade level (1-19+)
		4) Average grade level	Grade level (1- 19)
Content Quality	Accuracy	Is there conflicting information provided when compared to other reliable sources?	Mostly not accurate Mostly accurate Completely accurate
	Coverage How comprehensive is the cancer information provided with respect to:		
		Is "the cancer" (i.e., lung cancer, melanoma) clearly defined?	Yes No
		Are current figures provided regarding the annual incidence or overall prevalence of "the cancer" (lung cancer, melanoma)?	Yes No
		Is the etiology of "the cancer" (i.e. lung cancer, melanoma) or its risk factors clearly identified?	Yes No
		Are prevention strategies for "the cancer" (i.e., lung cancer, melanoma) clearly identified?	Yes

APPENDIX B: WEBSITE ASSESSMENT TOOLS (VERSIONS 1.0, 2.0 AND 3.0)

Categories	Subcategories	Questions	Answer choices
			No
		Are treatment strategies for each stage clearly described?	Yes No
		Is the prognosis for each stage clearly described?	Yes No
	Objectivity	Is there bias or opinion expressed when a writer interprets or analyzes facts? (e.g., Is there use of viewpoints or persuasive language?)	Yes No

APPENDIX C: WEBSITES FOR REVIEW

Appendix C-1: Examples of excluded and included websites:

Examples of excluded websites:

Figure 3: Example of excluded website due to no unique information, i.e. merely providing links to link to news article with no specific patient information (http://www.theglobeandmail.com/life/health-and-fitness/health/scientists-find-lung-cancer-can-lie-hidden-for-20-years/article21017726/)

APPENDIX C: WEBSITES FOR REVIEW

Figure 4: Excluded website not intended for the purposes of general patient education and dedicated to advertising a treatment (http://my.pearlpoint.org/resources/i-have-lung-cancer-what-should-i-eat?gclid=CN2q7_aLssECFQGqaQodbpcAMQ)

APPENDIX C: WEBSITES FOR REVIEW
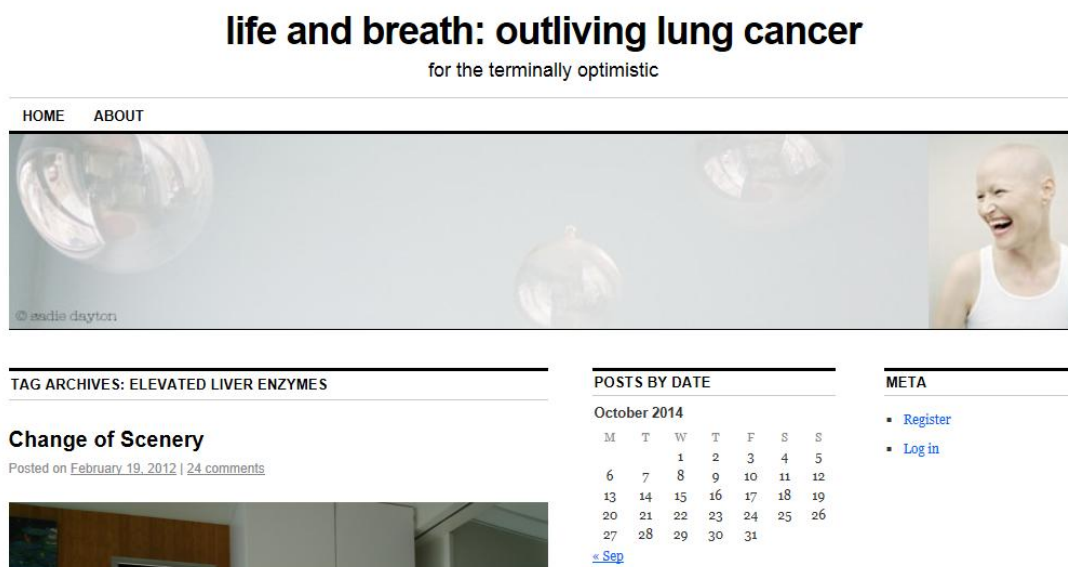
Figure 5: Excluded website not intended for the purposes of general patient education i.e. blog (http://outlivinglungcancer.com/tag/elevated-liver-enzymes/)

APPENDIX C: WEBSITES FOR REVIEW

Included Websites:

Figure 6: Included website intended for the purposes of general patient education (http://www.cdc.gov/cancer/lung/)

APPENDIX C: WEBSITES FOR REVIEW

Figure 7: Included website intended for the purposes of general patient education
(http://www.lungcancer.org/)

APPENDIX C: WEBSITES FOR REVIEW

APPENDIX C-2: LIST OF 100 LUNG CANCER WEBSITES REVIEWED

www.womenshealth.gov/faq/lung-cancer.cfm
ipaki.com/content/html/34/1067.html
www.allaboutmalignantmesothelioma.com/lung-cancer.htm
www.lungusa.org
www.radiologyinfo.org/en/info.cfm?pg=lungcancer
www.cancerinfohq.com/cancer-treatment/lung-cancer-treatment/?kid=644997&ad=18378917013
www.phac-aspc.gc.ca/ccdpc-cpcmc/cancer/publications/lung_e.html
http://cancer.stanford.edu/lungcancer/small.html & http://cancer.stanford.edu/lungcancer/nonsmall.html
ethnomed.org/patient_ed/cancer/lung/VietnameseLungCancer/xplain.html
www.lungcancerguidebook.org/book.htm
www.lung.ca/diseases-maladies/cancer-cancer_e.php
www.nlm.nih.gov/medlineplus/lungcancer.html
www.nih.gov/
https://www.google.com/health/ref/Lung+Cancer
bodyandhealth.canada.com/channel_condition_info_details.asp?disease_id=177&channel_id=2022&relation_id=
16665
www.meds.com/lung/lunginfo.html
http://www.pdrhealth.com/disease/disease-mono.aspx?contentFileName=BHG01ON02.xml&contentName=Lung+Cancer&contentId=93
www.patient.co.uk/showdoc/27000571/
www.cancer.org/docroot/home/index.asp
www.cancer.ca
www.cancerhelp.org.uk/help/default.asp?page=2787
nihseniorhealth.gov/lungcancer/toc.html
http://www.lungcancercap.org/
www.cdc.gov/cancer/lung/
www.clevelandclinic.org/health/health-info/docs/0000/0025.asp
www.quit-smoking-stop.com/lung-cancer.html
www.meb.uni-bonn.de/cancer.gov/CDR0000062932.html and http://www.meb.uni-bonn.de/cancer.gov/CDR0000062945.html
www.onehealthylifestyle.com/physical-health/diseases/lung-cancer.aspx
http://chealth.canoe.ca/channel_condition_info_details.asp?disease_id=177&channel_id=12&relation_id=1619
health.yahoo.com/lungcancer-symptoms/lung-cancer-symptoms/healthwise--tm1357.html
www.mdanderson.org/patient-and-cancer-information/cancer-information/cancer-types/lung-cancer/index.html
www.associatedcontent.com/article/1307979/small_cell_lung_cancer.html
healthguide.howstuffworks.com/lung-cancer-dictionary.htm
www.lungcancercoalition.org/
www.roycastle.org/content/LeftNavigation/AboutLungCancer.aspx
www.cancercouncil.com.au/editorial.asp?pageid=43
www.mylungcancerguide.com/
www.vivaprime.com/health/conditions-and-diseases/lung-cancer.aspx
www.hc-sc.gc.ca/hc-ps/tobac-tabac/body-corps/disease-maladie/lung-poumon_more-plus-eng.php
www.lunghealtharticles.info/lung-cancer.html
www.preventcancer.org/education2c.aspx?id=2702
www.healthywomen.org/healthtopics/lungcancer
www.lungevity.org/content/?section=547&subcat2=553&page=553
www.ucsfhealth.org/adult/medical_services/cancer/lung/index.html
www.webmd.com/lung-cancer/default.htm
www.intelihealth.com/IH/ihtIH/WSIHW000/9339/24413.html
www.healthinsite.gov.au/topics/Lung_Cancer
www.lungcancer.org
www.csmc.edu/1518.html
www.ricancercouncil.org/cancer-info/lung-cancer-facts.php
www.lungcanceralliance.org/
www.cancer.net/patient/Cancer+Types/Lung+Cancer
lungresearch.info/result.php?Keywords=Lung
www.health.uab.edu/14856/ and http://www.health.uab.edu/14795/
www.oncolink.org/types/types.cfm?c=9
www.tobacco.org/articles/category/lung_cancer/
www.mayoclinic.com/health/lung-cancer/DS00038

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http://www.sk.lung.ca/content.cfm?edit_realword=lungcancer
www.euphix.org/object_class/euph_lung_cancer.html
www.merck.com/mmhe/sec04/ch057/ch057a.html
http://www.lancastergeneral.org/content/greystone_36127.htm
www.lungcancercanada.ca/
www.smokinglungs.com
medicineworld.org/cancer/lung/index.html
http://www.britannica.com/EBchecked/topic/351515/lung-cancer
www.cancercare.on.ca/cms/One.aspx?portalId=40955&pageId=42869
www.umm.edu/respiratory/lungcan.htm
www.nationallungcancerpartnership.org/
www.medicinenet.com/lung_cancer/article.htm
www.symptomfind.com/diseases-conditions/lung-cancer/
www.netwellness.org/healthtopics/lung/lungcancer.cfm
http://www.uptodate.com/patients/content/topic.do?topicKey=~Q6bO5IwvWRvb
www.oncologychannel.com/lungcancer/diagnosis.shtml
www.wrongdiagnosis.com/l/lung_cancer/intro.htm
www.ahrq.gov/clinic/uspstf/uspslung.htm
www.knol.google.com/k/jessica/lung-cancer/tC006oKs/pXw2xg?domain=knol.google.com&locale=en#
www.chestjournal.org/content/123/1_suppl
www.cancernews.com/lung.htm
www.emedicine.medscape.com/article/279960-overview and http://emedicine.medscape.com/article/280104-overview
www.aacr.org/home/public--media/for-the-media/fact-sheets/organ-site-fact-sheets/lung-cancer.aspx
www.bccancer.bc.ca/default.htm
www.nice.org.uk/guidance/index.jsp?action=byID&r=true&o=10962
www.willroberts.com/lungcancer/index.html
www.en.wikipedia.org/wiki/Lung_cancer
www.answers.com/topic/lung-cancer
www.lungcancer.about.com/
www.metrohealth.org/body.cfm?id=1635
www.emedicinehealth.com/lung_cancer/page3_em.htm
www.cancerbackup.org.uk/Cancertype/Lung
www.bbc.co.uk/health/conditions/cancer/typescancer_lung.shtml
www.tirgan.com/lung.htm
www.medicalnewstoday.com/sections/lung_cancer/
http://www.rtanswers.org/treatment/disease/lung_cancer.htm
www.cancer.gov/cancertopics/wyntk/lung
www.mskcc.org/mskcc/html/376.cfm
www.sirweb.org/patients/lung-cancer/
www.decodeme.com/lung-cancer
www.netdoctor.co.uk/diseases/facts/lungcancer.htm
www.lungcancercircleofhope.org/
www.cancerpage.com/articles/default.asp?id=4&subarea=Your_Treatment

APPENDIX C: WEBSITES FOR REVIEW

APPENDIX C-3: LIST OF 100 MELANOMA WEBSITES REVIEWED

http://www.cancer.gov/CancerInformation/CancerType/melanoma

http://www.cancer.gov/cancertopics/wyntk/melanoma

http://dermnetnz.org/doctors/lesions/melanoma.html#obj

http://en.wikipedia.org/wiki/Melanoma

http://www.mayoclinic.com/health/melanoma/DS00439

http://www.medicinenet.com/melanoma/article.htm

http://melanoma.com/

http://www.nlm.nih.gov/medlineplus/ency/article/000850.htm

http://skincancer.org/Melanoma/

http://www.aad.org/public/publications/pamphlets/sun_malignant.html

http://www.answers.com/topic/malignant-melanoma

http://www.britannica.com/EBchecked/topic/373755/melanoma

http://cancer.about.com/od/melanoma/f/whatismelanoma.htm

http://www.cancer.net/patient/Cancer+Types/Melanoma

http://www.clevelandclinicmeded.com/medicalpubs/diseasemanagement/dermatology/cutaneous-malignant-melanoma/

http://daviddarling.info/encyclopedia/M/melanoma.html

http://ehealthmd.com/library/melanoma/MEL_whatis.html

http://emedicine.medscape.com/article/1100753-overview

http://www.healthscout.com/ency/68/187/main.html

http://www.melresproj.com/net/index.html

http://merck.com/mmpe/sec10/ch128/ch128e.html

http://skincarephysicians.com/skincancernet/melanoma.html

http://skincheck.org/index.htm

http://skinsite.com/info_melanoma.htm

http://www.ucsfhealth.org/adult/medical_services/cancer/skin/conditions/Melanoma/signs.html

http://www.melanomafoundation.org/facts/Facts.htm

http://ohiohealth.com/bodymayo.cfm?id=6&action=detail&ref=1247

http://www.umm.edu/skincancer/melanoma.htm

http://www.webmd.com/melanoma-skin-cancer/default.htm

http://afraidtoask.com/skinCA/skinmalignant.html

http://mamashealth.com/cancer/melanoma.asp

http://www.melanoma.co.za/D_doccnr_MFS.asp

http://tiffanysmelanomafoundation.org/whatismelanoma.htm

http://www.everydayhealth.com/skin-cancer/malignant-melanoma-risk-factors.aspx

http://www.wrongdiagnosis.com/m/melanoma/intro.htm

http://www.uwo.ca/oncology/undergraduate/pdf_documents/Melanoma.pdf

http://aboutmelanoma.com/index.html

http://www.meb.uni-bonn.de/Cancernet/CDR0000062917.html

http://www.melanomaintl.org/melanoma_info/

http://www.healthcentral.com/encyclopedia/408/187.html

http://fccc.edu/cancer/pdq/English/Patients/MelanomaTreatment.html

http://www.mdanderson.org/patient-and-cancer-information/cancer-information/cancer-types/melanoma/index.html

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http://adam.about.com/reports/Melanoma-and-other-skin-cancers.htm

http://www.cigna.com/healthinfo/hw206547.html

http://metrohealth.org/body.cfm?id=1636

http://melanoma.ca/

http://www.womenshealthmatters.ca/centres/cancer/melanoma/index.html

http://familydoctor.org/online/famdocen/home/common/cancer/types/666.html

http://www.melanoma.org/learn-more/melanoma-101/facts-and-information-about-melanoma-melanoma-101

http://www.aimatmelanoma.org/

http://www.aocd.org/skin/dermatologic_diseases/melanoma.html

http://bodyandhealth.canada.com/channel_condition_info_details.asp?disease_id=86&channel_id=12&relation_id=10830

http://www.cancer.ca/Canada-wide/About%20cancer/Types%20of%20cancer/What%20is%20melanoma.aspx?sc_lang=en

http://www.cancer.org/cancer/skincancer-melanoma/overviewguide/melanoma-skin-cancer-overview-what-is-melanoma?sitearea=cri&viewmode=print&

http://canceranswers.com/Melanoma.html

http://www.macmillan.org.uk/Cancerinformation/Cancertypes/Melanoma/Melanoma.aspx

http://www.cancerboard.ab.ca/Treatment/CancerInformation/Melanoma/

http://www.cancercompass.com/melanoma-information.htm

http://www.cancercouncil.com.au/editorial.asp?pageid=56

http://cancernews.com/articles/melanoma.htm

http://www.caring4cancer.com/go/melanoma

http://chealth.canoe.ca/channel_condition_info_details.asp?disease_id=86&channel_id=12&relation_id=1619

http://courses.washington.edu/hubio567/melanoma/

http://dermatology.about.com/cs/melanoma/a/melanoma.htm

http://www.dermatology.ca/patients_public/info_patients/skin_cancer/malignant_melanoma.html

http://dermatology.org/molemelanoma/introduction.html

http://www.dermatologychannel.net/skincancer/melanoma/index.shtml

http://emedicine.medscape.com/article/280245-overview

http://www.fhcrc.org/research/diseases/melanoma/

http://health.yahoo.net/channel/melanoma.html

http://www.healthline.com/adamcontent/melanoma#causesincidenceandriskfactors

http://www.healthlinkbc.ca/kb/content/major/hw206547.html#hw206866

http://healthnewsflash.com/conditions/melanoma_cancer.htm

http://intelihealth.com/IH/ihtIH/WSIHW000/8297/24556/211187.html?d=dmtHealthAZ

http://kidshealth.org/parent/medical/cancer/melanoma.html

http://lancastergeneral.org/content/greystone_36962.htm

http://www.mahalo.com/melanoma

http://www.medicalnewstoday.com/articles/154322.php

http://melanomacenter.com/whatis/whatis_melanoma.html

http://merck.com/mmhe/sec18/ch216/ch216d.html

http://www.mskcc.org/mskcc/html/390.cfm

http://www.naturalhealthontheweb.com/melanoma/treatment.html

http://nyp.org/health/melanoma.html

http://oncolink.org/types/article.cfm?c=18&s=63&ss=497&id=8600&p=1

http://thedoctorsdoctor.com/diseases/melanoma_disease.htm

http://www.phac-aspc.gc.ca/cd-mc/cancer/melanoma_skin_cancer-cancer_peau_melanome-eng.php

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http://skincancerguide.ca/melanoma/index.html

http://www.meb.uni-bonn.de/Cancernet/CDR0000062713.html

http://bccancer.bc.ca/PPI/TypesofCancer/Melanoma/default.htm

http://virtualcancercentre.com/diseases.asp?did=513

http://www.skinsight.com/adult/melanoma.htm

http://www.uptodate.com/patients/content/topic.do?topicKey=~aZhxeY09go9p

http://raysahelian.com/melanoma.html

http://thesmartfoundation.ca/default.aspx?PageID=1003

http://wikidoc.org/index.php/Melanoma

http://www.oncologychannel.com/skincancer/melanoma/index.shtml

http://www.umgcc.org/cutaneous_program/melanoma.htm

http://wiki.medpedia.com/Melanoma

http://www.umm.edu/ency/article/000850.htm

http://cancerhelp.org.uk/type/melanoma/

APPENDIX D: DETAILED RESULTS OF ANALYSIS OF LUNG AND MELANOMA WEBSITES

APPENDIX D1: RESULTS OF APPLICATION OF TOOL TO 100 PATIENT INFORMATION WEBSITES FOR LUNG CANCER

This appendix presents the results of the tool application to the first 100 websites for lung cancer.

Website Affiliations of Lung Cancer Websites

The origin of the sites was classified into five categories as follows: Commercial (.com), non-profit organization (.org), government (.gov), academic (.edu), and other (e.g. personal). The most frequent administrators of lung cancer patient information websites are commercial (45%) and non-profit organizations (36%) (Fig.D1a). The remainder, which constituted less than one-quarter of websites, were managed by government (12%), academic (4%) and other (1%) administrators.

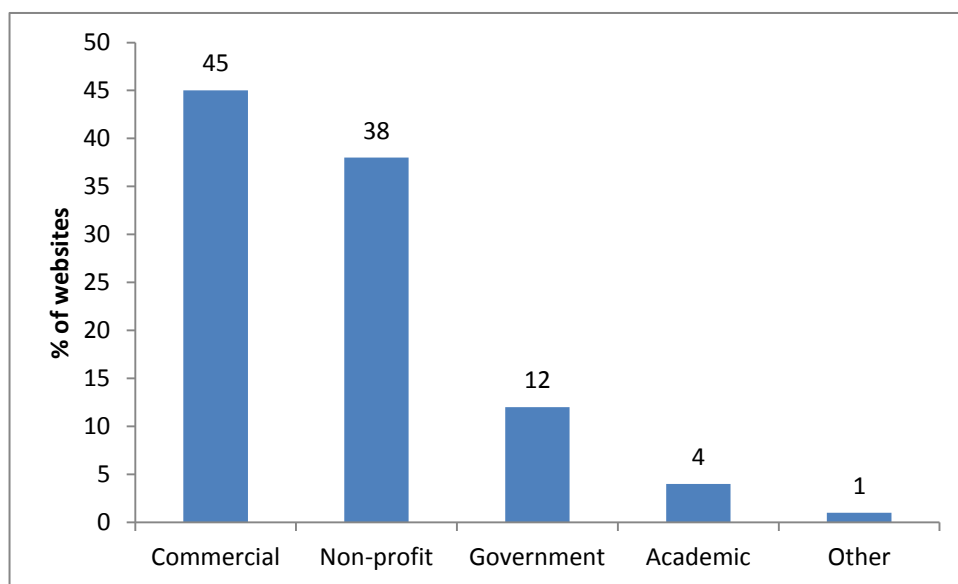**APPENDIX D: DETAILED RESULTS OF ANALYSIS OF LUNG AND MELANOMA WEBSITES**

Figure 8– Website affiliations of one-hundred lung cancer websites
Administrators of the ranked websites were classified into five categories: Commercial (.com), academic/ university (.edu), government (.gov), non-profit organization/ charity (.org), other (e.g. personal).

Accountability of Lung Cancer Websites

The accountability evaluation consisted of four components: authorship, attribution, disclosure and currency. Most websites declared authorship (90%), with 49% of authors indicating their credentials. Furthermore, ninety-three percent (93%) of sites disclosed ownership, sponsorship and/or advertising. However, less than half (46%) cited their references within the body or at the end of the document, with only 35% having used an acceptable range of sources (defined as 3 or more). Finally, fifty-

APPENDIX D: DETAILED RESULTS OF ANALYSIS OF LUNG AND MELANOMA WEBSITES

eight percent (58%) of sites stated a creation or modification date. Only half of the

websites (51%) had updated their content within the last two years. The links provided

on the websites were checked for accessibility, with 14% of sites found to have at least

one inaccessible link and 52% having three or more accessible links.
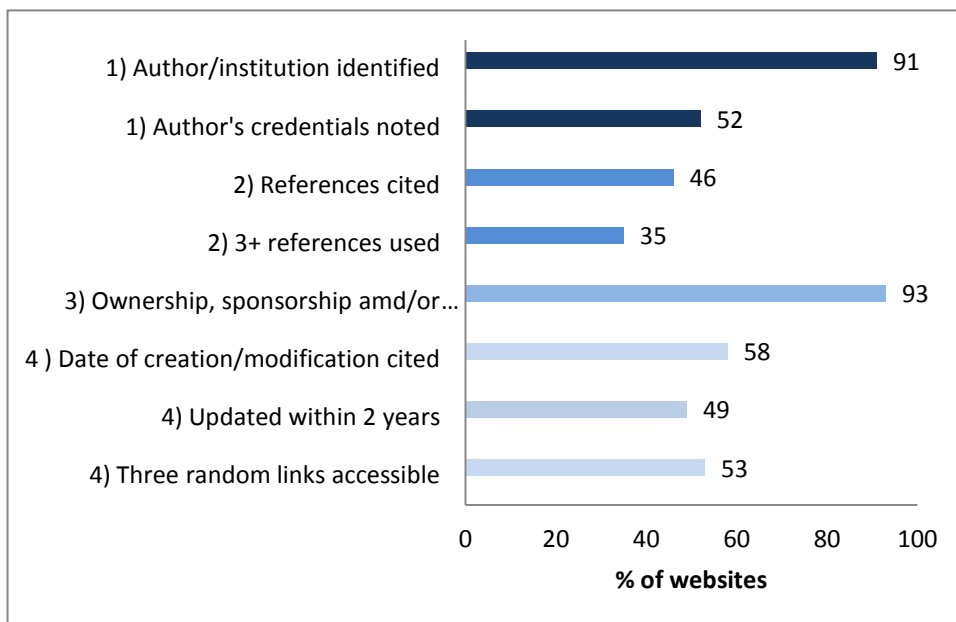

Figure 9– Assessment of accountability for 100 lung cancer websites
Accountability was further divided into four subcategories: 1) authorship (authors and their credentials); 2) attribution (citation of references, and range and reliability of sources); 3) disclosure (of site ownership, sponsorship and advertising); and 4) currency (date of creation / modification displayed and up-to-date within the last two years, and accessibility of links when provided).

**APPENDIX D: DETAILED RESULTS OF ANALYSIS OF LUNG AND MELANOMA
WEBSITES**

Interactivity and Structural Organization of Lung Cancer Websites

The majority of websites (54%) used three or more interactive components

(defined as site search engine, queries webmaster, discussion boards, audiovisual and

educational support). The most common interactive components were inquiries to a

webmaster or author (93%) and a within- site search engine (73%). One-quarter (26%)

of sites had a discussion board or forum, while 31% offered audiovisual and 30%

educational support. Structure and organization of sites was evaluated by the number of

structural tools, namely headings, subheadings, diagrams/ pictures/ tables, hyperlinks,

and absence of advertising, used in presenting the lung cancer information.   The vast

majority of websites applied four or more structural tools (76%).

Readability of Lung Cancer Websites

Readability of sixty-seven percent (67%) of sites was at an average education

level between grades 9 and 11, with an age of easy understandability of 14-18 years.

Notably, over a quarter of websites (26%) required some post-secondary education

based on average grade level. Table XIV shows the mean values and standard

deviation for the readability outcomes of the readability tests.

APPENDIX D: DETAILED RESULTS OF ANALYSIS OF LUNG AND MELANOMA WEBSITES

TABLE XIV –MEAN AND STANDARD DEVIATION MEASURES FOR THE READABILITY ASSESSMENT OF THE STUDIED WEBSITES.

Readability Tool	Mean	Standard Deviation
Flesch-Kincaid Grade Level Score	10.0	3.0
Flesch-Kincaid Readability Index*	57.7	13.1
SMOG Index†	9.6	2.1
Average Grade Level	11.29	2.7

* **Flesch-Kincaid Readability Index:** Gives a score range from 0 - 100. A higher score reflects higher legibility (i.e. a greater reading ease).

† **SMOG Index Interpretation:** Education level (SMOG Grade) – Low – literate (0-6), junior high school (7-8), some high school (9-11), high school graduate (12), some college (13-15), university degree (16), post-graduate studies (17-18), post-graduate degree (19+) (32).

APPENDIX D: DETAILED RESULTS OF ANALYSIS OF LUNG AND MELANOMA WEBSITES

Content Quality of Lung Cancer Websites

The majority of websites provided baseline information that was mostly accurate (80%) when compared to both UpToDate.Inc and the NCCN guidelines. Seventeen percent (17%) were deemed somewhat accurate with one reported statement being inconsistent with these peer-reviewed evidence-based sources. Coverage of lung cancer was deemed sufficient for 91% of sites that addressed 3 to 5of the following subtopics: definition, incidence/ prevalence, etiology/ risk factors, screening, diagnosis, staging, prognosis and treatment. Nine (9%) of websites covered only one to two of the aforementioned subtopics. Significant bias or author opinion was identified in 6% of sites.

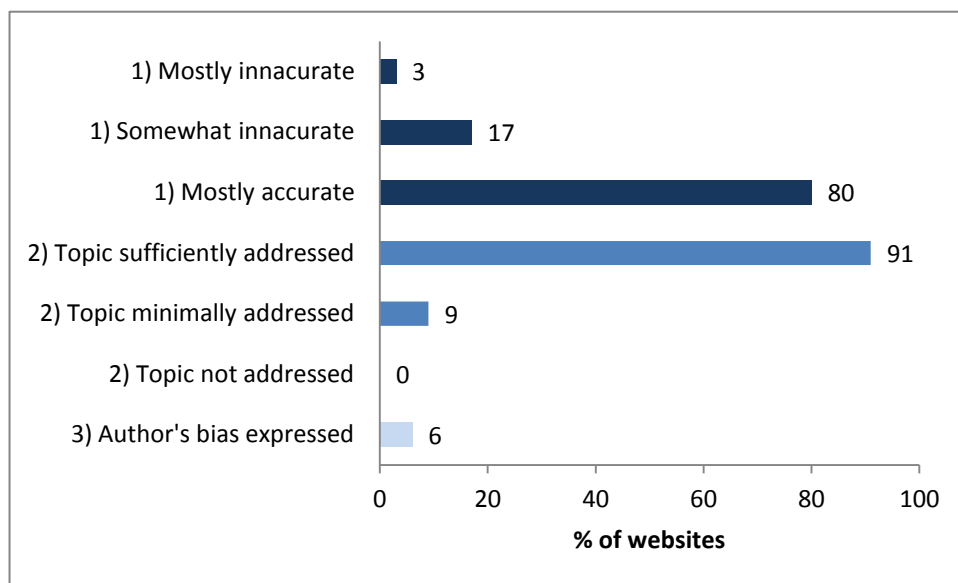# APPENDIX D: DETAILED RESULTS OF ANALYSIS OF LUNG AND MELANOMA WEBSITES

Figure 10 – Assessment of content quality of one-hundred lung cancer websites
Content quality was further divided into three subcategories: 1) accuracy (congruence of information with UpToDate.Inc and the NCCN guidelines; 2) coverage (comprehensiveness of lung cancer information provided, including definition, incidence, prevalence, etiology, risk factors, screening, diagnosis, staging. prognosis and treatment); and 3) objectivity (author's expression of bias or opinion).

APPENDIX D: DETAILED RESULTS OF ANALYSIS OF LUNG AND MELANOMA WEBSITES

APPENDIX D2: RESULTS OF APPLICATION OF TOOL TO 100 PATIENT INFORMATION WEBSITES FOR MELANOMA

This appendix presents the results of the tool application to 100 melanoma websites

Website Affiliations of Melanoma Websites

The origin of the studied sites was classified into five categories as follows: Commercial (.com), non-profit organization (.org), government (.gov), academic (.edu), and other (e.g. personal). The most frequent administrators of melanoma patient information websites are commercial (48%) and non-profit organizations (29%) (Fig.D2a). The remainder, which constituted less than one-quarter of websites, were managed by government (8%), academic (5%), and other (10%) administrators.

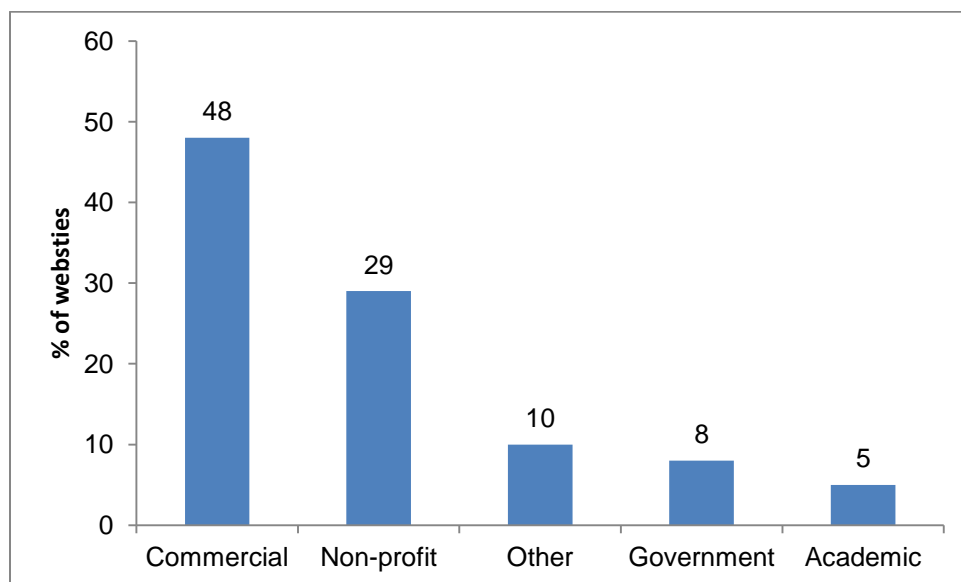**APPENDIX D: DETAILED RESULTS OF ANALYSIS OF LUNG AND MELANOMA WEBSITES**

Figure 11– Website affiliations of one-hundred melanoma websites
Administrators of the ranked websites were classified into five categories: commercial (.com), academic/ university (.edu), government (.gov), non-profit organization/ charity (.org), other (e.g. personal).

APPENDIX D: DETAILED RESULTS OF ANALYSIS OF LUNG AND MELANOMA WEBSITES

Accountability of Melanoma Websites

The accountability evaluation consisted of four components: authorship, attribution, disclosure and currency. Approximately half of websites declared authorship (50%), with 51% of authors indicating their credentials and 58% indicating affiliations. Less than a third (31%) cited their references within the body or at the end of the document, with only 27% using an acceptable range of sources (defined as three or more). Disclosure was commonly disclosed, with 91% of sites disclosing ownership, sponsorship and/or advertising.
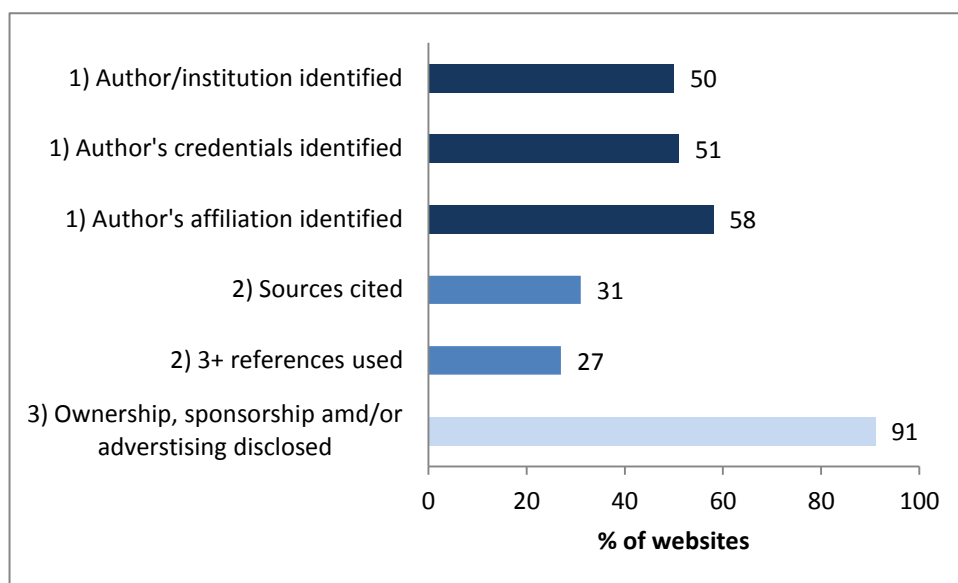

Figure 12 – Assessment of accountability for 100 melanoma websites. The percentage of websites indicating: 1) authorship (authors and their credentials); 2) attribution (citation of references and range and reliability of sources) and 3) disclosure (of site ownership, sponsorship and advertising.

APPENDIX D: DETAILED RESULTS OF ANALYSIS OF LUNG AND MELANOMA WEBSITES

With respect to currency, 80% of websites specified a date of creation. Less than half (45%) had updated their content within the last 2years. Fifty-one percent (51%) did not specify date or had updated more than 4 years ago.
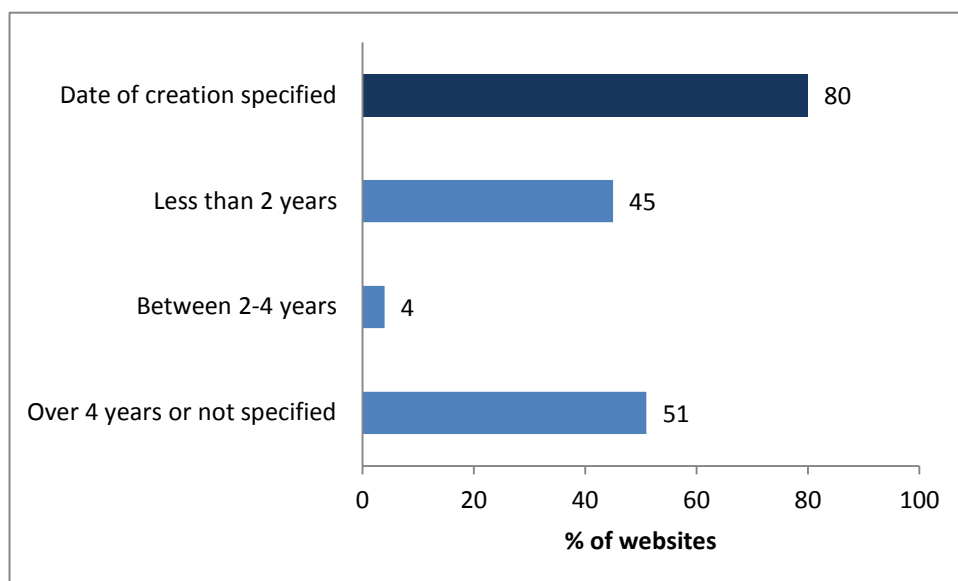

Figure 13 – Assessment of currency for 100 melanoma websites

APPENDIX D: DETAILED RESULTS OF ANALYSIS OF LUNG AND MELANOMA WEBSITES

Fifty percent (50%) of websites provided 1 or more external links. The links provided on the websites were checked for accessibility. The vast majority of websites that provided external links still had 50% or more of the links still active.

Interactivity and Structural Organization of Melanoma Websites

The most common interactive components were inquiries to a webmaster or author (87%) and a within-site search engine (76%). Approximately one-quarter (24%) of sites had a discussion board or forum, while 56% offered audiovisual support. Only 9% offered educational support. Structure and organization of sites was evaluated by the number of structural tools, namely headings, subheadings, diagrams/ pictures/ tables, hyperlinks, and absence of advertising, used in presenting the melanoma information.   The majority of websites included 4 or more structural tools (61%).

Readability of Melanoma Websites

The average grade level required for understandability was 10 (mean Flesch-Kincaid Score 10.4, mean SMOG 9.8). Notably 10% of websites required a grade 12 or higher level post-secondary education for readability. Table XV shows the mean values and standard deviation for the readability outcomes of the readability tests.

APPENDIX D: DETAILED RESULTS OF ANALYSIS OF LUNG AND MELANOMA WEBSITES

TABLE XV –MEAN AND STANDARD DEVIATION MEASURES FOR THE READABILITY ASSESSMENT OF THE STUDIED WEBSITES

Readability Tool	Mean	Standard Deviation
Flesch-Kincaid Grade Level Score	10.4	2.1
Flesch-Kincaid Readability Index*	54.2	10.8
SMOG Index†	9.8	1.7

* **Flesch-Kincaid Readability Index:** Gives a score range from 0 - 100. A higher score reflects higher legibility (i.e. a greater reading ease).

† **SMOG Index Interpretation:** Education level (SMOG Grade) – Low – literate (0-6), junior high school (7-8), some high school (9-11), high school graduate (12), some college (13-15), university degree (16), post-graduate studies (17-18), post-graduate degree (19+) (32).

Content of Melanoma Websites

The majority of websites provided baseline information that was mostly accurate (86%) when compared to both UpToDate.Inc and the NCCN guidelines. Seventeen percent (17%) were evaluated as somewhat accurate, with one website inconsistent with these peer-reviewed evidence-based sources.

With respect to coverage, the definition of melanoma and etiology of melanoma were well described in the resources with 93% and 91% of websites respectively covering these topics. Prevention was covered in approximately three-quarters of the websites (72%). There were weaknesses in information with respect to treatment by

APPENDIX D: DETAILED RESULTS OF ANALYSIS OF LUNG AND MELANOMA WEBSITES

stage (36%) and prognosis (15%). Significant bias or author opinion was not identified

in any site.

APPENDIX D3: RESULTS OF RE-APPLICATION OF FINAL TOOL WITH REVISED/EXPANDED DEFINITIONS OF AUTHORSHIP, CURRENCY, LINKS AND COVERAGE TO 100 PATIENT INFORMATION WEBSITES FOR LUNG CANCER

This appendix represents the expanded results of the tool application to the first 100

websites for lung cancer. Four (4) sites were no longer functioning; hence, the analysis

is for 96 sites.

Revised Accountability Criteria of Lung Cancer Websites

In the revised tool, identification of the author was separated from the

identification of institution/affiliations. When these were separated, this did alter the

identification of author, such that 50% (48/96) of websites actually identified an author

(compared with 90% in the first analysis identifying an author or institution). When an

author was identified, 77% (37/48) identified their institutional or commercial affiliations.

Thus it appeared that potential differences could occur in interpretation if one were to

look for a specific author or for details of a particular body/institution authoring the work.

Currency was also re-analyzed with the expanded definitions. By separating

creation from modification date, the data was again altered. In comparison with the

original analysis, that focused on creation or modification date (58% of websites), only

14% (13/96) of websites specifically indicated a **creation** date, whereas 54% (52/96)

APPENDIX D: DETAILED RESULTS OF ANALYSIS OF LUNG AND MELANOMA WEBSITES

specified a modification date. Some websites contained both a creation and modification date.

With respect to the expanded definition of links, clarifying the definition for active links and separating from number of links, over 73% of websites contained links to external sites. Of those with links, 90% had more than half of their links accessible.

Revised Coverage of Lung Cancer Websites

Expanding the definitions of the coverage of the topics provided a much richer description of the gaps and strengths in the lung cancer information. In the initial analysis, 91% of sites addressed 3 to 5 of the following subtopics: definition, incidence/ prevalence, etiology/ risk factors, screening, diagnosis, staging, prognosis and treatment. Nine (9%) websites covered only one to two of the aforementioned subtopics. When the sites were re-analyzed it appeared that the vast majority provided a definition of lung cancer and etiology (92% for both); however less than half of the sites included information on prognosis (46%) and incidence (40%).

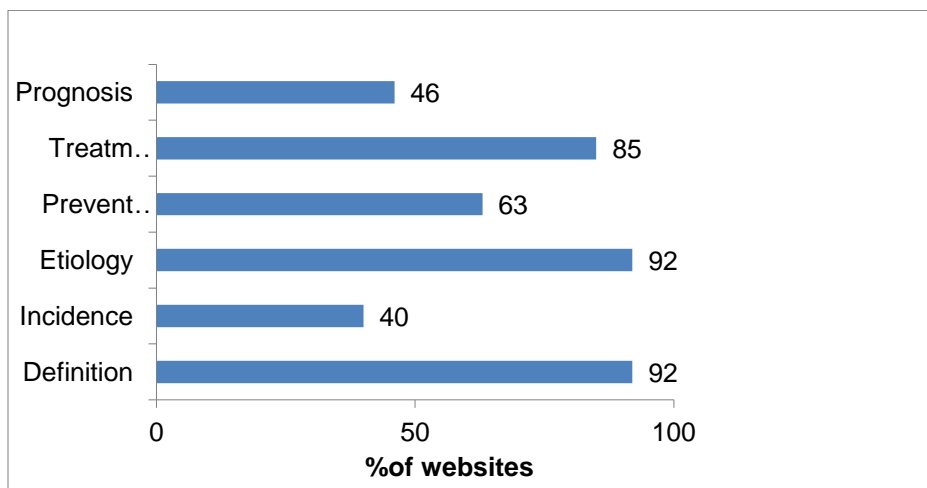**APPENDIX D: DETAILED RESULTS OF ANALYSIS OF LUNG AND MELANOMA WEBSITES**

Figure 14– Revised assessment of coverage for 96 lung websites

VITA

NAME: Paris-Ann Ingledew

EDUCATION: B. SC. Cellular, Molecular, Microbial Biology, University of Calgary, 1998
MD, University of British Columbia, 2002
FRCPC, Radiation Oncology Residency, University of British Columbia, 2007
MHPE, University of Illinois at Chicago, 2015

FACULTY APPOINTMENT:

Clinical Assistant Professor, UBC Faculty of Medicine, Department of Surgery/Division of Radiation Oncology and Developmental Radiotherapeutics

PROFESSIONAL QUALIFICATIONS:

Fellow of Royal College of Physicians and Surgeons of Canada, Radiation Oncology, June 2007
License to practice medicine, College of Physicians and Surgeons of British Columbia, 2007 to present
Licentiate of the Medical Council of Canada, July 2002

HONORS:

Shane Fellowship, B.C. Cancer Agency, 2007- 2010
Betty Rice Lung Cancer Research Award, B.C. Cancer Agency, 2006
International Association for the Study of Lung Cancer, Lung Partnership Young Investigator Travel
        Award, 2006
Canadian Association of Radiation Oncologists Annual Meeting, Top
        Resident Poster, 2006
Canadian Association of Radiation Oncologists Annual Meeting, Jean Roy Memorial Award, 2005
Connective Tissue Oncology Society, Young Investigator Award, 2005
American Society for Clinical Oncology, Novartis Oncology Young
        Canadian Investigators Research Award, 2005
Florence E. Heighway Medical Research Scholarship, UBC Medical
        School, 2000-2002
Alberta Heritage Foundation for Medical Research Studentship, 1997
University of Calgary, Chancellor's Scholarship 1994-1998

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