CONSUMER EMPOWERMENT THROUGH METADATA-BASED INFORMATION QUALITY REPORTING: THE BREAST CANCER KNOWLEDGE ONLINE PORTAL

<table>
<thead>
<tr>
<th>Journal:</th>
<th>Journal of the American Society for Information Science and Technology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manuscript ID:</td>
<td>JASIST-2008-08-0245</td>
</tr>
<tr>
<td>Wiley - Manuscript type:</td>
<td>Research Article</td>
</tr>
<tr>
<td>Date Submitted by the Author:</td>
<td>03-Aug-2008</td>
</tr>
</tbody>
</table>
| Complete List of Authors: | McKemmish, Sue; Monash University, Centre for Organisational and Social Informatics  
Manaszewicz, Rosetta; Monash University, Centre for Organisational and Social Informatics  
Burstein, Frada; Monash University, Centre for Organisational and Social Informatics  
Fisher, Julie; Monash University, Centre for Organisational and Social Informatics  
Monash University, Centre for Organisational and Social Informatics |
| Keywords: | metadata < data < (documents by information content, purpose) < (document types) < portals < web sites < World Wide Web < Internet < telecommunications networks < (communications networks), quality < (general attributes) < (attributes) |

John Wiley & Sons, Inc.
CONSUMER EMPOWERMENT THROUGH METADATA-BASED INFORMATION QUALITY REPORTING: THE BREAST CANCER KNOWLEDGE ONLINE PORTAL

Professor Sue McKemmish (Contact Author)
Faculty of Information Technology
Monash University
PO Box 97,
Caulfield East, Victoria, 3145
Australia
Sue.McKemmish@infotech.monash.edu.au
Tel: +61 3 99031060
Fax: +61 3 9903 1077

Rosetta Manaszewicz
Faculty of Information Technology
Monash University
PO Box 97,
Caulfield East, Victoria, 3145
Australia
Email:
Tel:
Fax: +61 3 99031077

Associate Professor Frada Burstein
Faculty of Information Technology
Monash University
PO Box 97,
Caulfield East, Victoria, 3145
Australia
Email: Frada.Burstein@infotech.monash.edu.au
Tel: +61 3 9903
Fax: +61 3 99031077

Associate Professor Julie Fisher
Faculty of Information Technology
Monash University
PO Box 97,
Caulfield East, Victoria, 3145
Australia
Email: Julie.Fisher@infotech.monash.edu.au
Tel: +61 3 9903
Fax: +61 3 9903 1077
Abstract

Consumer empowerment and the role of the expert patient in their own health care, enabled through timely access to quality information, have emerged as significant factors in better health and lifestyle outcomes. Governments, medical researchers, healthcare providers in the public and private sector, drug companies, health consumer groups and individuals are increasingly looking to the Internet to distribute health information, communicate with each other, and form supportive or collaborative online communities. Evaluating the accuracy, provenance, authority and reliability of web-based health information is a major priority. The Breast Cancer Knowledge Online Project (BCKOnline) explored the individual and changing information and decision support needs of women with breast cancer and the issues they face when searching for relevant and reliable health information on the Internet. To address them, it developed a personalized information portal driven by a metadata repository of user-sensitive resource descriptions. This paper focuses on the innovative metadata-based quality reporting feature of the BCKOnline Portal, and concludes that it is timely to consider the inclusion of quality elements in resource discovery metadata schema, especially in the health domain.

Keywords: health, Internet, breast cancer, quality reporting, resource discovery

INTRODUCTION

Reliable, up-to-date information is crucial today - particularly when it comes to health matters...

...While the Net provides a massive amount of useful information, it also leads users to information of questionable quality. (HealthInsie, 2006)

Websites and portals are increasingly important sources of information for health consumers. Portals such as Australian HealthInsite (http://www.healthinsite.gov.au), and US HealthFinder (http://www.healthfinder.gov/) are witness to this trend, as is a recent Australian government-commissioned e-health strategy report which identified “access to reliable, good-quality, general health
care information to enable self-management” as a key stakeholder objective (Boston, 2004, 31). Health consumer and advocacy groups, and “online self-helpers” are also increasingly using the Internet to share medical and experiential knowledge about particular diseases, to network with each other and form online communities for support, collaboration and advocacy (Ferguson, 2007). There is also increasing recognition of a range of issues relating to Internet-based health information provision, including information overload, relevance, quality and reliability (Zeng et al., 2004), with health information consumers experiencing difficulty in finding relevant information and assessing its quality. Approaches to supporting quality assessment include the development of ethical standards for information providers, and tools such as quality checklists, rating instruments, scoring systems, quality seals and certifications which rely on experts assessing resource quality on evidence-based criteria (Gagliardi, 2002; Risk, Dzenowagis, & Petersen, 2001; Risk & Petersen, 2001; Wilson, 2002).

Providing health information consumers with value-add information about the resource in the form of metadata is another approach. Such an approach can reference the medical evidence-base of a resource, its provenance and authority, as well as providing the health consumer with information that enables her to assess the resource’s “fitness for purpose”, linked to its relevance and timeliness in the context of her needs and circumstances. It also enables recognition of the role played by the value systems and priorities of individual information seekers.

This paper describes the metadata-based approach to quality reporting taken in the Breast Cancer Knowledge Online Portal, a personalized information portal for women with breast cancer, launched in 2004 (BCKOnline: www.bckonline.monash.edu.au). The consumer-initiated BCKOnline Project was funded by an Australian Research Council grant. It involved a unique partnership of academic researchers from Monash University, breast cancer service providers from the state government agency BreastCare Victoria, members of the advocacy Breast Cancer Action Group, and members of the breast cancer community (defined in this Project as women with breast cancer, their family, friends and carers), the future users of the Portal. The research involved user information needs and literary warrant analysis; knowledge domain mapping and concept modelling; evaluation,
selection and description of information resources; and portal design, development and evaluation. It was underpinned by extensive user consultation and participation.

The findings of the BCKOnline Project revealed that members of the breast cancer community shared the concerns of other health information consumers about the quality, provenance, authoritativeness and reliability of online health information, and that the proposed solutions, for example accreditation of sites or the use of quality ratings based on various codes, did not necessarily meet their requirements. The BCKOnline Portal addresses these concerns by including a quality reporting feature which highlights the quality attributes of each individual item retrieved by referencing the credentials of creators, contributors, and publishers; the nature of any related review process; the attribution and citation of sources; the evidence base for the resource; the purpose of the resource; whether the resource contents are controversial or represent a consensus view; and the currency of the resource. This paper discusses the development of the quality reporting feature of the BCKOnline Portal within the broader context of the BCKOnline Project. Outcomes of usability testing of the portal and user feedback have highlighted the value placed by users on the quality reports. Given that issues relating to the quality of online resources are common to the whole health sector, the final section of the paper suggests that it is timely to consider the inclusion of quality elements in resource discovery metadata schema used in the health domain. It may be that similar issues arise whenever users or consumers are accessing information resources online to assist them in critical decision making in other domains as well.

**QUALITY OF ONLINE HEALTH INFORMATION**

Research relating to Internet searches for health information highlights both a growing demand and user concerns with quality. Luo & Najdawi (2004) report that 52 million Americans search for health information at least monthly. Numerous surveys and reports have quantified the number of users who regularly consult health sites. Estimates vary, but the most cited US report concludes that 71% of
Internet users between 50 and 64 years old have gone online for health information, compared with 53% of those between 18 and 29 (Fox, 2002; Madden & Fox, 2006). Other surveys report that the number of online health seekers in the United States has grown from 66% in 2002 to 74% in 2005 (Harris, 2005), and that the number of health-related topics on Yahoo grew to 74,000 by May 2005 (Dannecker & Lechner, 2006). Research from the United Kingdom reports that in one year, the health website Surgery Door recorded 3,680,453 page views (Huntington, Nicholas, & Williams, 2003). European results, whilst not reporting such massive proportions, still place the figures of individuals seeking online health information at 23% of all users, with the percentages for some individual countries listed as: Netherlands (41.4%); Sweden (38.7%); Finland (33.5%) and Luxembourg (32.4%) (Spadaro, 2003).

Research literature on consumer trust in Internet health information reports major concerns with its quality and reliability, and it is estimated that less than 50% of online health information has been reviewed by an expert (Bomba, 2005; Childs, 2004; Eysenbach & Kohler, 2002; Luo & Najdawi, 2004). Further, little additional information is provided to health consumers about the information source, its provenance and authority (HON, 2006; Sillence, Briggs, Fishwick, & Harris, 2004). Studies investigating the quality of disease specific websites support these findings, e.g. cancer (Cumbo et al., 2002; Fogel, 2002; Kunst, 2002; Paultler, 2001), cardiology (Dickerson, Flaig, & Kennedy, 2000); depression (Griffiths & Christensen, 2002); obstetrics and gynaecology (Hardwick & MacKenzie, 2003; Okamura, 2002); genetics (Kieffer, 2001); asthma (Croft & Peterson, 2002); and alternative therapies (Ernst & Schmidt, 2002; Martin-Facklam, 2002). Some studies have reported that the misinformation contained in many sites may constitute a health risk to the consumer (Kunst, 2002; Martin-Facklam, 2002; Schmidt & Ernst, 2004).

Breast cancer specific studies have also documented dissatisfaction amongst women and their families with the timeliness, relevance, and quality of breast cancer information provision. The BCKOnline Project was in part a response to Australian and international studies that highlighted the fact that
information provision remains amongst the two highest unmet needs of women with breast cancer and their families (Coulter, Entwistle, & Gilbert, 1999; Girgis, 2000). More recent Australian studies have reported higher levels of satisfaction with overall information provision, but continue to highlight the lack of customized information to meet the specific needs of some members of the Australian breast cancer community, e.g. younger women (Davey & Butow, 2006), rural women (Davis, Williams, Redman, White, & King, 2003) and women with advanced disease (Aranda et al., 2005), and gaps in information provision, e.g. in relation to complementary medicines, long-term management of illness, and psycho-social support (Mallinger, Giggs, & Shields, 2004; Thewes, Butow, Girgis, & Pendlebury, 2004).

THE BCKOnline PROJECT

The inter-related factors of information overload, quality, reliability and relevance were the most frequently cited concerns of the women with breast cancer interviewed during the user information needs analysis study of the BCKOnline Project (Burstein, Fisher, McKemmish, Manaszewicz, & Malhotra, 2005):

… if you’re going to go into the Internet and try to find a site that is going to tell you something, how do you know that it’s valid information? Just by reading it? I think that’s a lot of hogwash. (BCKOnline Interviewee 13)

I knew that there was a lot of rubbish on there [the Internet] and I didn’t know how I would be able to find the right information: whether or not there would be a lot of websites available to me or whether there would just be people flogging their own opinions … You’re looking for something that pertains to you and you alone, and information does tend to be very general.” (Interviewee 17)
“A lot of the time the information that you get, until it suddenly is part of what you’re going through, is not relevant …” (BCKOnline Interviewee 3)

For these women, their family, friends and carers, the ability to access timely, relevant and reliable information is a vital component in patient empowerment, in facilitating decision making, better treatment compliance, and improved medical, societal, and general health outcomes. It is particularly critical for health consumers with life-threatening illness who are grappling with the medical and psycho-social effects of the disease and anxieties associated with them. The BCKOnline user information needs analysis confirmed that information needs change dramatically along the breast cancer disease trajectory, with factors such as age, lifestyle, information preferences, and location also significantly impacting on user needs (Williamson & Manaszewicz, 2003).

The BCKOnline Project aimed to address the diverse and changing information needs of women with breast cancer and the issues they face relating to quality, reliability and relevance when searching for health information on the Internet by building a personalized information portal.

*Personalization is a toolbox of technologies and application features used in the design of an end-user experience. Features classified as "personalization" are wide-ranging, from simple display of the end user's name on a Web page, to complex catalogue navigation and product customization based on deep models of users’ needs and behaviour.* (Kramer, Noroha, & Vergo, 2000)

Personalization adds value by providing information that matches the user’s needs – “the right content in the right format to the right person at the right time” (Ho & Tam, 2005) – and enables users to judge a resource’s quality and reliability, e.g. by providing information about its provenance and authority. Personalization is a key factor in user satisfaction, contributing to the success or failure of a system (Ferran, More, & Minguillon, 2005, 210). To address the challenge of building a personalized information portal, the Project brought together a multidisciplinary team of researchers and...
technologists from the information systems, information and knowledge management, and computer science disciplines; domain knowledge experts – women from the Breast Cancer Action Group with in-depth knowledge of relevant information sources, information management credentials and personal experience of breast cancer; and users – health information providers and consumers from the breast cancer community. All of these constituencies were also represented on the Project Advisory Group.

The BCKOnline Portal

The underlying architecture of the BCKonline Portal is depicted in Figure 1.

![BCKOnline portal components](image)

**Figure 1 Breast Cancer Knowledge Online Portal**

The Portal includes a personalized End User Interface based on user profiles and information preferences. The BCKOnline Metadata Schema provides a template for the description of 1500 resources, selected on the basis of user information needs analysis and domain expertise. The descriptions are authored by knowledge domain experts, assisted by the Metadata Authoring Tool, and stored in the Metadata Repository. The descriptions are linked to online resources, the Portal’s “virtual information resource repository”. The Portal’s search engine uses the metadata-based resource descriptions to match a user’s profile and information preferences with relevant resources. The primary
search strategy is based on User Profiles (age, disease stage and who the information is for); User Preferences for forms of information (plain brief, plain detailed, scientific brief and scientific detailed); and Information Types (medical, supportive and personal stories); and key word. The Portal also provides search options based on major subject areas and keywords alone. When a user initiates a search, she is provided with a list of resources, a brief description of each resource, a quality report and the option to view a full metadata description. Based on this information, she can then decide which resources are most relevant and reliable in relation to her information needs (Burstein, McKemmish, Fisher, Manaszewicz, & Malhotra, 2006).
Breast Cancer Online Research Methodology

The BCKOnline Project pioneered a user sensitive research design, integrating methodologies from the social sciences, knowledge management and information systems, including user information needs analysis (Williamson 2002), user centred and value sensitive approaches (Friedman, 2004; Friedman, & Borning, 2006; Preece, Rogers, & Sharp, 2002), and systems development research techniques (Burstein, 2002) within an interpretivist framework. The research design was informed by a philosophical view of what it means to be user-sensitive – to place the user’s needs and values at the heart of system design and development.

Underpinning the research design was a set of values shared by the project team and project participants:

- The potential audience for the BCKOnline Portal is not homogeneous. It represents a diversity of information needs, format preference, level of ‘readability’ requirements, and type of material desired.

- Knowledge is contextual – that is, its value to the individual is a dynamic interplay of personal, social, psychological, educational, and cultural factors.

- Quality, relevance, reliability and trustworthiness are contingent, not absolute. They are not attributes of an information resource per se, but of the relationship between the resource, an information seeker, their needs, and the values and life experiences they bring to their assessment of what is relevant, reliable and trustworthy for their purposes at the time of a search. The role of the portal is partly to provide them with sufficient information about a resource to make an assessment about its “fitness for purpose”.

- The perspectives of people with direct and/or personal experience of breast cancer provide a valuable information resource and insight which both complements and enhances the scientific/biomedical view of breast cancer treatment, management and research.
Members of the breast cancer community who participated in the Project are regarded as partners in the Project, not subjects of the research.

The BCKOnline’s iterative research processes are illustrated in Figure 2 and briefly described below.

User needs and values are at the centre of design considerations and are embodied in the collaboration between researchers, technologists, domain knowledge experts (DKE), and users.

**Figure 2 Iterative Research Processes in BCKOnline User Sensitive Research Design**

**User Information Needs Analysis**

A sample of 59 women with breast cancer, 11 breast care nurses and 7 family members, was purposively selected to represent the various demographic variables to be included in the user needs analysis (Williamson 2002). Interviews and focus groups were used to identify and understand the information needs, values and purposes of the target audience, how women searched the Internet for information, and any problems they encountered. The user information needs analysis provided understandings of the changing information needs of women with breast cancer, the relationship between these needs and the individual’s circumstances, the values individuals bring to assessing the relevance and quality of resources to their needs and purposes, and their experiential knowledge of the disease. Critical information quality-related requirements included the precision of the retrieval of...
information relevant to an individual’s circumstances, for example information specific to a disease stage (early, recurring or advanced) or age group; a choice of the type and format of information retrieved by the search, e.g. personal stories or medical information, brief or scientific, graphic or just text; and provision of information about the quality of the resource.

**Literary Warrant Analysis**

The literary warrant for professional practice is made up of authoritative sources, which are recognised and valued by experts in the field. Such authoritative sources may be found in the law, codes of ethics, standards, the professional and scholarly literature, and literary texts (Gilliland & McKemmish, 2006). Literary warrant analysis was applied in the BCKOnline Project to the analysis of quality codes for online health information. Researchers and domain knowledge experts applied the findings of the user information needs and quality codes analyses to the development of the BCKOnline Metadata Schema; the specification of criteria for the evaluation and selection of information resources; and portal design.

**Domain Knowledge Modelling and Representation**

Domain mapping and conceptual modelling of crucial constructs such as information quality, reliability and relevance supported the development of the BCKOnline Metadata Schema, which provides a template for the standardized description of breast cancer knowledge resources, and the portal’s metadata-based quality reporting feature. The domain experts also drew on the content analysis of user focus group and interview transcripts, including the experiential knowledge of users, to specify which categories of resources should be included in the portal and the number of resources per category.

**Resource Evaluation, Selection and Description**

Selection criteria relating to disease stage, age group, subject category, the representation of a range of resource formats and types, and the inclusion of Australian content were applied in evaluating and selecting 1500 Internet-based resources for inclusion in the Portal. Resource descriptions and quality reports were developed using the BCKOnline Metadata Schema. The outcomes of these processes populated the Metadata Repository of the portal with resource descriptions which enable the Portal to
match user profiles and search queries with relevant resources, and provide summary information and quality reports on the resources retrieved.

**User Consultation**

User consultation informed all stages of the research. Usability tests were conducted to assess the Portal’s functionality and effectiveness from the perspective of women with breast cancer or their carers and to help identify any usability problems. Two focus groups were also convened to review the usefulness of the Portal, for example the quality of the information provided, whether the information they accessed had helped in any decisions they had to make, and which search options they preferred.

**System Design, Development and Testing**

Finally, the BCKOnline Project used iterative system design, prototyping, development and evaluation techniques to build and test the Portal and its personalization features (Burstein 2002).

**QUALITY REPORTING IN THE BCKOnline PORTAL**

**What is Quality Health Information?**

The BCKOnline Project metadata-based approach to quality reporting was based on literary warrant analysis of current evidence-based quality standards and codes, as well as the findings of the user information needs analysis and user consultation, and input from the Project partners, domain knowledge experts and Project Advisory Group. *From the perspective of the medical profession, quality is inextricably linked with the hierarchical structure of evidence-based medicine, a field in which the “gold standard” is represented by meta-analyses of randomized controlled trials. Various seals of approval, guidelines, voluntary codes of ethics, and third party accreditation are the tools whereby the information seeker is alerted to the quality of the located online resources. However, there is considerable diversity of opinion as to what constitutes quality, and as yet no consensus view has emerged. The various standards and codes such as the Health on the Net HonCode, the AMA Guidelines for Medical and Health Information Sites, and DISCERN represent the diversity of current*
thinking. A major gap in the current discourse is detailed analysis of the applicability of such schemes to the full range of information types and formats of interest to health information consumers. More pertinently, scant attention has been directed to how such guidelines support the information seeking behaviours and needs of the health consumer, or to what extent current models of quality criteria empower patients to make better health decisions.

How and on what basis do consumers decide which information they will place their trust in? Early research on this issue was inconclusive and contradictory. It was frequently based on random phone sampling, online survey submissions or case studies made up of healthy participants with no specific or critical health information or decision-making need, or employing hypothetical scenarios where participants are required to locate answers to specific health questions. The issue of motivation, especially in life threatening diseases, and consideration of the role this may play in the careful sifting of information were largely absent. A number of these studies concluded that ease of use and design aesthetics outweighed issues relating to the quality of information content (Eysenbach, Powell, Kuss, & Eun-Ryoung, 2002). By contrast, in the BCKOnline Project online information quality, reliability and trustworthiness emerged as major issues, particularly because the information sought was being used to support critical medical and lifestyle decision making in the context of life-threatening illness.

In results that differ dramatically from the earlier studies, but confirm the BCKOnline Project findings, several more recent studies (Adams, de Bont, & Berg, 2006; Esquivel, Meric-Bernstam, & Bernstam, 2006; Ferguson, 2007) have reported that online health information seekers are discerning in their use of online resources, are fully cognisant of the potential for misleading and inaccurate information, and have developed elaborate strategies for determining the reliability of information for their purposes:

In concentrating on how patients fail to follow prescribed measures for checking reliability, other authors have failed to notice the importance of the patients’ directed processes of searching for answers to highly specified questions. The current approach to the reliability of
information neglects to consider that information must be applied to the individual situation
and that this has consequences for how patients assess reliability. (Adams et al 2006, p. 67)

Not surprisingly these studies, like the BCKOnline Project, also found that the task of evaluating the accuracy and reliability of online health information is firmly grounded in both the needs and subjective value systems of the individual user. If evaluation of quality is contingent rather than absolute, a function of the relationship between the information resource, the information seeker and her information needs, not an attribute of the resource per se, quality reporting needs to extend beyond the approach taken by quality codes, seals of approval and accreditation tools. It needs to provide information additional to that relating to the medical evidence-base of a resource, its provenance and authority. Quality reporting in the Portal was therefore designed to support users in their assessments of the “fitness for purpose” of a resource, linked to its relevance, contextual significance and timeliness, and recognises the role played by the value systems and priorities of individual information seekers.

BCKOnline Project findings also highlight the wide range and format of resources which participants in the user information needs analysis and domain experts felt were important to both physical and psychological progress. For many users, lay or experiential knowledge was seen as an important component in the psychosocial experience of illness, as well as providing a lived repository of information capable of informing medical decision-making. Subsequently, the growing body of literature on self-help and support groups and the role of information provision within such groups have testified to the evolution of experiential expertise and its significance to many health information consumers (Ferguson, 2007; Hoybye, Johansen, & Tjornhoj-Thomsen, 2005; Radin, 2005; Rini et al., 2007). If, as in the BCKOnline Portal, access to resources relating to both medical and experiential knowledge of illness is provided, then quality reporting also needs to extend beyond criteria for assessing the biomedical pedigree or evidence-based status of resources to information relevant to the
assessment of materials which may not have full evidence-based status, or may represent an area which, at the present time, is viewed as controversial or alternative.

**Analysis of Quality Standards and Codes**

The BCKOnline Project selected standards and codes for analysis which were frequently cited in the literature, had international standing, were specifically developed or adapted to an online environment, and represented the full diversity of then current thinking on quality assurance from an evidence-based perspective. Those that are available via a current website, and are still maintained and updated by the organizations that issued them, or a successor organization which has taken on that role,¹ are analysed below, namely:

- Health on the Net – HonCode of Conduct (Health, 1997)
- American Medical Association – Guidelines for Medical & Health Information Sites on the Internet (American, 2000)
- URAC health web site accreditation (URAC, 2003), issued 2003)
- OMNI – Organising Medical Networked Information (OMNI, 1999), issued 1999), now part of Intute, which provides a gateway to health and life sciences resources and services, including OMNI
- DISCERN (University, 1997)

Differences in their respective purpose and mission, enforcement protocols and intended audience are presented in Table 1.

¹ The European Community, Hi-Ethics and MedCertain quality criteria were also analysed, but are not included here. The European Community quality criteria are available via [www.ec.europa.eu/information_society/eeurope/ehealth](http://www.ec.europa.eu/information_society/eeurope/ehealth), but this is an
Table 1: Quality Health Information Codes (adapted from Risk & Petersen, 2001)

Each code enunciates a set of quality criteria which deal with various aspects of online health information. Generally, the accrued criteria can be classified under three separate categories relating to information content, assuring consumer privacy and technological or web-design features such as navigability. The BCKOnline analysis, presented in Table 2, focused on criteria for evaluating the quality of information content with reference to Silberg’s four core quality accountability markers – authorship, attribution, disclosure and currency (Silberg, Lundberg, & Musacchio, 1997).

Table 2: Information Content Quality Criteria

Most of the codes include criteria relating to Silberg’s core quality accountability markers, though some have more rigorous requirements than others in relation to providing information about the credentials of the authors, and references to authoritative sources and published findings. The greatest divergence is evident in the attribution category with the most stringent being HonCode which calls for a published bibliography, regardless of intended audience, or the scientific nature of the material. The AMA criteria simply require that citations be presented in a “manner appropriate to the audience”. It is also important to note that though the codes relating to sites intended for a general audience all include authorship and attribution of sources as fundamental requirements, few government and health organizations worldwide adhere strictly to such recommendations when the information is directed towards the lay consumer. Examples include the US National Cancer Institute’s web site, the Australian Government gateway HealthInsite, and the British NHS Direct.

archived website; the Hi-Ethics and MedCertain sites no longer exist. The MedCertain criteria are still available via the
Although more recent literature is replete with calls to improve user health literacy relating to information accuracy and reliability (Lorence & Greenberg, 2005), none of the codes include criteria which would directly assist users in determining the scientific ‘accuracy’ of the resource (Bernstam et al., 2008) or the controversial nature of certain treatments or protocols. Nor is there any mechanism which would alert users to the existence of divergent opinion across international practice guideline recommendations. This is illustrated in the differing international protocols relating to the efficacy of mammographic screening for women under 50 (Garber, 2003). Furthermore, there is evidence that even within the same geographic and cultural boundaries, expert opinion differs (Craigie, Loader, Burrows, & Muncer, 2002). The user needs to be alerted to a lack of medical consensus, or to know that a view is controversial so that she can make informed decisions about the quality of such information and what importance to attach to it. In this manner, individual autonomy and decision-making capacity is respected and enhanced.

Finally, the criteria which relate to currency are also somewhat problematic in that providing modification dates or information about when a site is updated do not necessarily address the concept of currency (very old information can still be current; very new information can already be out of date).

**BCKOnline Findings on User Perspectives on Quality Accountability Markers**

How does the lay information seeker view authorship, attribution, disclosure and currency? More importantly, do these markers in themselves provide sufficient guarantees for the health information consumer of the quality and reliability of the information? Do they provide a user with sufficient information on which to make an assessment of whether the resource is reliable and can be trusted for her purposes? The findings of the BCKOnline Project indicate that, although authorship, attribution, disclosure and currency are important, they do not necessarily guarantee the quality and reliability of the information. The user needs to be aware of the limitations of these markers and to seek additional information from other sources to make informed decisions about the quality of the information.
disclosure, and currency are significant markers of quality for health information consumers, they do not address all the aspects of quality that are of concern – they are significant but not sufficient. Moreover the criteria defined by the codes for evaluating authorship, attribution and currency appear to be based on a limited view of these concepts. It is possible that the reasons for this are twofold – firstly a view that quality is an objective attribute of the information resource; and secondly an underlying assumption that health consumers have basically identical needs for information resources that largely derive from the biomedical field and are predominantly text-based.

To sum up, the BCKOnline findings suggest that quality can in part be assessed using factors such as provenance and authoritativeness for which authorship and attribution provide useful markers. However, quality is generally perceived as contingent rather than absolute, a function of the relationship between the information resource, the information seeker and her information needs, not an attribute of the resource per se. The “fitness for purpose” of a resource is integrally related to a definition of quality which brings into play factors such as relevance, contextual significance and timeliness as well as the value systems and priorities of individual information seekers.

**METADATA-BASED QUALITY REPORTING**

The quality reporting feature of the BCKOnline Portal is based on the BCKOnline Metadata Schema and includes a Quality element. The quality report draws on the Quality element and a number of other elements to provide the user with information about the quality of each individual item retrieved.

**The BCKOnline Metadata Schema**

A resource discovery metadata schema identifies in a standardized way metadata elements or descriptors needed to describe an information resource in ways that enable users to find information that is relevant and timely. At present the international de facto standard for describing documents on
Table 3 The BCKOnline Metadata Schema

the web, the Dublin Core (http://purl.oclc.org/metadata/dublin_core), has limited capacity to provide information that would enable users to judge a key component of relevance, the quality of the resources they discover. The Australian National Standard AGLS (Standards, 2002) is an extension of Dublin Core, and includes an Audience element. For this reason, AGLS was used as the basis for the BCKOnline Metadata Schema. Many metadata schemas support descriptions of information resources that are “resource-centric”—describing resources in terms of attributes like Creator, Title, and Subject. The BCKOnline Metadata Schema includes these resource descriptors, but also “user-sensitive descriptors” relating to the target audience and information quality. To achieve the latter it further extended the Dublin Core and AGLS sets to include a Quality element. Its user-sensitive descriptive capability was also enhanced by the development of BCKOnline Encoding Schemes for the Audience and Quality elements. Schema analysis, metadata modelling, concept mapping of metadata schema and standards, and empirical instantiation, which populates models with examples (McKemmish, Acland, Ward, & Reed, 1999) were used to develop the BCKOnline Schema’s semantic structure. Table 3 presents the Schema, highlighting its extensions and enhancements (BCKOnline, 2004).

The BCKOnline Audience Encoding Scheme supports the primary search strategy of the portal which is based on user profiling. The portal interface enables the user to build a profile based on the attributes defined by the Audience and Resource Type element qualifiers. Then, by searching on the Audience and Type elements of the metadata record, it matches the selected profile with resources that contain information highly relevant to the target audience represented by the profile. User profiles can be built from the Age Group, Disease Stage, Information Preference, and User Type Audience qualifiers, and the Resource Type qualifiers. For example, if a user selects “plain” and “brief” as a presentation
format, then her search will not retrieve medical journal articles. If a young woman is looking for personal stories and accounts the resources retrieved will be of stories from women in her age group.

The BCKOnline Quality Element and Encoding Scheme

The semantics of the Quality element and related Encoding Scheme were derived from the Project’s knowledge mapping and conceptual modelling processes, literary warrant analysis of existing quality codes, user consultation and user information needs analysis relating to quality, and the knowledge of the domain experts. In designing the quality reporting feature, consideration was also given to the transparency, interpretation and user-friendliness of quality markers, including the need to limit them to a manageable number. The importance of such design principles are highlighted in subsequent research (Bernstam, Shelton, Walji, & Meric-Bernstam, 2005; Burkell, 2004). The Quality element enables the Portal to provide the user with a quality report relating to all the resources on the list of search results if she so desires. The user’s decision to proceed to select a resource from the list of search results and her evaluation of the reliability and trustworthiness of that resource for her purposes can be informed by the quality report. Table 4 provides details of the BCKOnline Encoding Scheme designed for use with the BCKOnline Quality element and its qualifiers, together with a commentary on the Scheme which takes into account more recent literature on the ways in which health information consumers assess quality and the value of experiential knowledge (as discussed in the section on What is Quality Health Information?).

[Table 4 should appear here]

Table 4: BCKOnline Quality Element Encoding Scheme

The Quality Report
Following the principles of transparency and disclosure of the BCKOnline Portal, the user has the option of viewing all of the metadata elements, including the Quality element and its qualifiers.

Figure 3 BCKOnline Search Results Display Screen

The Quality Report is designed for presentation to the user at the point where she sees the list of search results, as illustrated in Figure 3. It is constructed from all of the Quality qualifiers and structured according to the following order: creator, publisher, review process, attribution, evidence base, currency, purpose and balance. Two examples follow:

This material was created by a lay author and published by a consumer group. The content has undergone editorial review. References are not included and the subject matter represents
current personal opinion. The purpose is educational/informative and the controversial nature of some of the issues has been noted.

This material was created by clinicians and published by a medical organisation. The content has undergone editorial review. References are included and the subject matter represents current case/cohort evidence. The purpose is educational/informative and is of a non-controversial nature.

Usefulness and usability testing of the portal found that the users particularly appreciated the quality reporting feature. They felt that this value-added information increased their confidence in making a decision on health issues. They also felt empowered by having access to information in a user-friendly form which helped them to assess the quality and reliability of a resource in terms of their needs and circumstances.
FURTHER RESEARCH

Resource identification, selection and description processes, including quality reporting, as undertaken in the BCKOnline Project and described here, are resource intensive processes. Yet, the application of domain knowledge expertise to these processes is a critical component of the efficacy of the BCKOnline Portal. In order to develop robust and sustainable portals that incorporate metadata-driven quality reporting, a range of questions relating to support for the role of domain knowledge expert need to be addressed, e.g. can automated techniques replace in whole or in part the role of the domain knowledge expert in resource identification, selection and description, including quality reporting?

What aspects of domain expertise can be codified and represented in intelligent information technologies? What tools can be developed to support the role of the domain expert and the automated or semi-automated generation of metadata, including metadata relating to information quality? Further research to explore these issues is now underway in an Australian Research Council Discovery Project, the Smart Information Portal (SIP) Project relating to the development of smart and user sensitive information portals in the health domain generally.

CONCLUSION

As the Internet is increasingly being used by all stakeholders to distribute health information, communicate with each other, and form supportive or collaborative online communities, evaluating the accuracy, provenance, authority and reliability of web-based health information has become a major priority. A recently published White Paper on e-patients points to a paradigm shift in healthcare which will change the roles of medical professionals and expert patients,

Citizens with health concerns who use the Internet as a health resource, studying up on their own diseases … finding better treatment centers and insisting on better care, providing other
patients with invaluable medical assistance and support, and increasingly serving as important collaborators and advisors for their clinicians. (Ferguson, 2007, 17)

The BCKOnline Portal’s innovative metadata-based quality reporting feature facilitates information content quality evaluation by providing a more extensive range of quality markers for a wider range of information types, including both medical and experiential knowledge. It does so in a way which respects and enhances the personal autonomy and decision making capacity of health information consumers, thus contributing to the emergence of expert patients who are “equipped, enabled, empowered, and engaged” in their health care (Ferguson 2007). The approach adopted also recognizes that quality is not an attribute of an information resource per se, but of the relationship between the resource, the user, their purposes and their values. Given that issues relating to the quality of online resources are common to the whole health sector, it is likely that similar issues to those explored in relation to the breast cancer community arise whenever health information consumers are accessing information resources online. It may also be the case that users and consumers in other domains are concerned with the quality of information resources, as defined in the BCKOnline Project, when they are accessing information to assist them in critical decision making. It may therefore be timely to consider the inclusion of quality elements in resource discovery metadata schema to support quality reporting in personalized information portals, especially in the health domain.

ACKNOWLEDGEMENT

The BCKOnline Project was funded by an Australian Research Council Linkage Grant (2002-3), BreastCare Victoria - an initiative of the Victorian Department of Health and Human Services, the Breast Cancer Action Group Inc. (Vic).Chief Investigators of the BCKOnline project were: Professor Sue McKemmish, Associate Professor Frada Burstein, Associate Professor Julie Fisher, Dr. Kirsty Williamson and Ms June Anderson (FIT, Faculty of Information Technology, Monash University); Ms. Sue Lockwood (BCAG, Breast Cancer Action Group Vic). Other personnel included Research
Fellows Rosetta Manaszewicz (FIT & BCAG) and Fiona Ross (FIT), research students Pooja Malhotra, Jane Moon and Chan Cheah, and, system architect Dr Sergio Viademonte and programmer Andiwijaya Sumartono. The development of Breast Cancer Knowledge Online would not have been possible without the direct, personal contribution of women with breast cancer, their families and friends. The resulting portal owes much to this combined insight in living and coping with the disease. Their guidance has been invaluable in shaping both the content and functionality of the portal. Some of these women were incredibly ill, yet still determined to participate in a project which they believed would benefit others. All participants enriched this project with their thoughtful reflections and commitment. We are forever grateful for their altruism and dedication. Sadly, not all participants have been able to bear witness to the product of this commitment.

REFERENCES


<table>
<thead>
<tr>
<th>CODE</th>
<th>TYPE</th>
<th>ENFORCEMENT</th>
<th>AUDIENCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>HonCode</td>
<td>Voluntary code of conduct</td>
<td>Self regulation</td>
<td>General public</td>
</tr>
<tr>
<td>AMA</td>
<td>Voluntary code of conduct</td>
<td>AMA and self regulation</td>
<td>Webmasters, editors</td>
</tr>
<tr>
<td>URAC</td>
<td>Third party commercial accreditation</td>
<td>URAC</td>
<td>Organisations</td>
</tr>
<tr>
<td>OMNI</td>
<td>Third party evaluation (gateway approach)</td>
<td>Evaluation by expert committee prior to materials being posted</td>
<td>Students, researchers</td>
</tr>
<tr>
<td>DISCERN</td>
<td>Tool based assessment</td>
<td>Intended for use by consumer, website owners, content providers</td>
<td>General public</td>
</tr>
</tbody>
</table>

Table 1: Quality Health Information Codes (adapted from Risk & Petersen, 2001)
<table>
<thead>
<tr>
<th>CODE</th>
<th>AUTHORSHIP</th>
<th>ATTRIBUTION</th>
<th>DISCLOSURE</th>
<th>CURRENCY</th>
</tr>
</thead>
<tbody>
<tr>
<td>HonCode</td>
<td>All medical information presented on your web site must be attributed to an author and his/her training in the field must be mentioned.</td>
<td>Where does the information come from? What literature was used to gather information for the article? A bibliography must be included, with hypertext links if possible.</td>
<td>Your site must include a statement declaring its sources of funding. This is required of all sites, including personal sites with no external sources of funds.</td>
<td>Date of last modification must be included on every page of the site. For clinical articles, we recommend including the creation date as well.</td>
</tr>
<tr>
<td>AMA</td>
<td>A list of staff members and other individual (eg editorial board) responsible for content... should be posted on the site.</td>
<td>Reference material used to develop content should be cited in a manner appropriate for the audience.</td>
<td>Funding or other sponsorship for any specific content should be clearly indicated.</td>
<td>The dates that content is posted, revised, and updated should be clearly indicated.</td>
</tr>
<tr>
<td>URAC</td>
<td>For health content, the web site provides the name of the author and/or source of the material.</td>
<td>NONE</td>
<td>The web site discloses to users information regarding: significant financial investors and interests in the owner or website. If advertising or sponsorship is one of the funding sources, the web site discloses to users its advertising and sponsorship policies.</td>
<td>For health content the web site provides the date of the health content or its last update.</td>
</tr>
<tr>
<td>OMNI</td>
<td>Has an individual or group taken responsibility for the resource? Are they qualified to provide this information? Are contact details available?</td>
<td>Is the information supported by published research findings?</td>
<td>Is an organisation responsible for the information? Are any organisations associated with the resource, such as publishers, sponsors or funding agencies, reputable and recognised?</td>
<td>Is the information up-to-date? Is the information likely to be kept up-to-date? Where applicable, how frequently and/or regularly is the information updated? Is this appropriate to the type of information?</td>
</tr>
<tr>
<td>DISCERN</td>
<td>NONE</td>
<td>Is it clear what sources of information were used to compile the publication (other than the author or producer)?</td>
<td>NONE</td>
<td>Is it clear when the information used or reported in the publication was produced?</td>
</tr>
</tbody>
</table>

Table 2: Information Content Quality Criteria
<table>
<thead>
<tr>
<th>Elements</th>
<th>Qualifiers/Encoding Scheme</th>
<th>Elements</th>
<th>Qualifiers/Encoding Scheme</th>
</tr>
</thead>
<tbody>
<tr>
<td>DC Creator</td>
<td></td>
<td>DC Format</td>
<td></td>
</tr>
<tr>
<td>DC Publisher</td>
<td></td>
<td>DC Date</td>
<td></td>
</tr>
<tr>
<td>DC Contributor</td>
<td></td>
<td>DC Identifier</td>
<td></td>
</tr>
<tr>
<td>AGLS Availability</td>
<td></td>
<td>DC Rights</td>
<td></td>
</tr>
<tr>
<td>DC Title</td>
<td></td>
<td>DC Source</td>
<td></td>
</tr>
<tr>
<td>DC Language</td>
<td></td>
<td>DC Relation</td>
<td></td>
</tr>
<tr>
<td>DC Subject</td>
<td>BreastCare Victoria Glossary</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>BCKOnline Disease Trajectory</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>BCKOnline Key Words</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AGLS Audience</td>
<td>BCKOnline Qualifiers</td>
<td></td>
<td>BCKOnline Resource Type Encoding Scheme Medical; Supportive; Personal</td>
</tr>
<tr>
<td></td>
<td>Age Group (Under 40, 40-49, 50-69, 70 and over)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Disease Stage (Early, Recurrent, Advanced)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>User Type (Self, Friend, Child, Family Member)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Information Preference (Plain/Brief, Plain/Detailed, Scientific/Brief, Scientific/Detailed)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>BCKOnline Quality</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Credentials</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Review Process</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Attribution of Sources</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Evidence-basis</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Purpose</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Balance</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Currency</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Narrative</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 3 The BCKOnline Metadata Schema
### BCKOnline QUALIFIERS

<table>
<thead>
<tr>
<th>Credentials of Creator, Publisher, Contributor</th>
<th>COMMENTARY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lay Author</td>
<td>This qualifier is linked to the Silberg authorship quality marker and aims to provide the user with a range of easily understood descriptive tags relating to the credentials of contributors. Together with information about the identity and qualifications of those involved in producing the resource in the Creator, Publisher and Contributor elements, the Credentials qualifier enables assessment of the provenance and probable authority of the material. However it makes no judgement about the relative merits of these credentials. Some users may place greater credence in material that originates from consumer groups than in material provided by governments. For others a cancer organization may be seen as a source of more reliable information. Possible extensions to this list could include sub-categories of Lay Authors, e.g. “expert patients”, carers or patient advocates; and of health professionals, e.g. type of medical practitioner, nurse or other healthcare professional.</td>
</tr>
<tr>
<td>Clinician</td>
<td></td>
</tr>
<tr>
<td>Researcher</td>
<td></td>
</tr>
<tr>
<td>Consumer Group</td>
<td></td>
</tr>
<tr>
<td>Commercial Body</td>
<td></td>
</tr>
<tr>
<td>Educational Institution</td>
<td></td>
</tr>
<tr>
<td>Government Organisation</td>
<td></td>
</tr>
<tr>
<td>Medical Organisation</td>
<td></td>
</tr>
<tr>
<td>Cancer Organisation</td>
<td></td>
</tr>
</tbody>
</table>

### Review Process

<table>
<thead>
<tr>
<th>Review Process</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Editorial Board</td>
<td>Users who require substantial scientific-based information wish to read online journals or need to decide whether to pay for access to articles are not necessarily familiar with the merits of one publication over another. Given the profusion of available journals, the consumer and even the medical professional has no real means of assessing relative quality. In this context, and extending the concepts of authorship and attribution as represented in the quality codes, the existence of a review process and its nature may inform choice. The judgement as to whether material which has gone through a review process is more reliable, whether the existence of an Editorial Board gives the resource more legitimacy or authority, and the value of an Editor or a peer review process is left to the consumer. The proposed addition of Moderator, Post-publication and Audience Review Processes recognises the increasingly important role of listservs, bulletin boards, blogs and similar</td>
</tr>
<tr>
<td>Peer Review</td>
<td></td>
</tr>
<tr>
<td>Editor (proposed)</td>
<td></td>
</tr>
<tr>
<td>Moderator (proposed)</td>
<td></td>
</tr>
<tr>
<td>Post-publication Review Process</td>
<td></td>
</tr>
<tr>
<td>Audience Review Process</td>
<td></td>
</tr>
<tr>
<td>No process</td>
<td></td>
</tr>
</tbody>
</table>
Attribution of Sources

- Yes/No

Attribution of sources is also a Silberg core quality marker addressed by most quality codes, but websites do not routinely or consistently reference the sources of the information they provide, especially when the presumed audience is the lay person. As is the case with the other qualifiers provided here, the existence of references does not of itself ensure quality. However, it is a factor that users may wish to take into account when making their own assessment of the reliability and quality of a resource.

Evidence Basis

- Meta-analysis
- Randomised Clinical Trial
- Case/cohort Study
- Review
- Consensus Opinion
- Personal Opinion

Clinical practice guidelines and/or best practice may differ from country to country, as do the rating scales, e.g. there are 4 levels associated with Australian clinical guidelines, but 5 in the American standards. This qualifier does not provide quality ratings, but indicates the evidence-basis of a resource with reference to whether it presents medical knowledge or experiential knowledge, and whether it is based on research, best practice, personal opinion or personal experience. Possible extensions include providing information as to whether the site is accredited under any of the main standards or codes, the basis for a personal opinion (e.g. the personal experience of the illness as a patient, family member or carer, or the personal view of a healthcare professional or service provider), and more user-friendly and refined terms relating to the type of medical research involved (e.g. a multiple or single case study).

Purpose

- Educational or Informative
- Commercial (to be)

Concern over commercial exploitation and the potential of advertising parading as content on health information sites have led to a call for the disclosure of sponsorship in any quality assurance scheme. This qualifier links the issue of disclosure, another Silberg core quality marker, to purpose. It reports on the main objective of a
replaced by reference to whether resource includes Advertising)
- Reportage of Results
- Commentary (proposed)
- Review (proposed)
- Assessment or Evaluation (proposed)
- Discussion Forum
- Listserv (proposed)
- Bulletin Board (proposed)

<table>
<thead>
<tr>
<th>Balance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Controversial issue – noted</td>
</tr>
<tr>
<td>Controversial issue – not noted</td>
</tr>
<tr>
<td>Non-controversial issue</td>
</tr>
</tbody>
</table>

The question of balance is a contentious one, and it does not figure as a quality marker in the majority of recognized codes. Some codes define balance with reference to tone, objectivity, completeness or comprehensiveness. The aim of the BCKOnline Balance qualifier is simply to alert the user to whether the information contained in a resource is of a controversial nature or not, and whether, if it is, this is acknowledged in the resource. Beyond the use of this qualifier, the BCKOnline Portal also addresses the issue of balance by providing the user with the full spectrum of opinion relating to one specific treatment. For instance, if the user wishes to view personal anecdotes regarding the side effects of a particular drug, then she will be alerted to the existence of contrary voices.

<table>
<thead>
<tr>
<th>Currency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current</td>
</tr>
<tr>
<td>Non-current</td>
</tr>
</tbody>
</table>

Identifying dates of creation, modification, or the last posting of materials does not fully capture the concept of currency, the fourth Silberg quality marker. Obviously some materials may be years old, yet their efficacy as treatment protocols, or their representation as best practice might still apply. Standards or clinical practice
guidelines may be re-issued, but the content of the superceded standards or guidelines might still be current. Furthermore, personal reactions to the experience of serious illness could quite feasibly be timeless. Other materials may be current for only a short period of time. Hence this concept is far from adequately covered by any of the current codes. Unfortunately, although the Currency qualifier allows resources to be described as current or non-current in the sense referred to above, it remains problematic.

Table 4: BCKOnline Quality Element Encoding Scheme