Building a User Sensitive Intelligent Portal to Breast Cancer Knowledge to Meet Diverse Information Needs

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Abstract

The Internet provides access to a plethora of information, with health information being no exception. Portals for guiding users seeking health knowledge are proliferating. A major challenge in their development is filtering the information available in a user-sensitive way. The Breast Cancer Knowledge Online (BCKOnline) project addresses the challenge of meeting the diverse information needs of women with breast cancer and their families through the provision of timely, relevant and reliable information to support decision-making. This paper focuses on how the outcomes of user needs analysis and user-aware resource description will feed into building an intelligent portal prototype to breast cancer knowledge.

Keywords

Intelligent portal, Internet, information access and filtering, metadata schema, information resource description

INTRODUCTION

The concept of an information portal is not new, as pointed out by White (2000). An early manifestation can be seen in the online host services of the 1970s and 80s. These services aimed to be a one-stop shop or access point that pulled together data from a range of sources. White notes that today there is a wide range of information portals, and suggests that: "A feature of all these sites is that an expert, or a team of experts, in a particular area has created an information structure that assists the user in identifying relevant links." (White, 2000: 356) Portals are also not new in the health care and medical areas and there are many portals that provide gateways to information and services relating to many aspects of health (Markovitz, 2000). In Australia and the United States respectively, portals such as *HealthInsite* (http://www.healthinsite.gov.au) and *Healthfinder* (http://www.healthfinder.gov) signal recognition of the role such sites can play in delivering health and medical knowledge to the general Internet user. Increasingly portals are being designed to provide an intelligent interface between the user and relevant information resources by customising searches in order to target information that meets the needs of individual users. In spite of these developments, there is evidence of dissatisfaction amongst users with the relevance, timeliness and quality of information accessed via the web. Research has also demonstrated that customised, in-time access to quality health care, medical and related information is critically important as it impacts significantly on both health and life-style decisions. Governments throughout the world have championed the rise of consumer involvement in health care and the importance of access to information as a means of 'patient empowerment' and informed decision-making. For example, the National Health Information Management Advisory Council (1998) stated: "Consumers' access to information and the ability to make decisions about their own health and well-being are important rights. In

addition, there is a growing body of evidence to support the argument that greater consumer participation in health care improves clinical outcomes." A critical challenge facing the designers of intelligent portals is how to provide differentiated access to resources to meet the diverse and changing needs of individual users, and to "add-value" by providing information that also enables users to judge the quality and reliability of the resource.

There is a plethora of information resources available online for women with breast cancer and their families. How timely, relevant or suitable is the information they provide to the individual user? Is it equally comprehensible to the drop-out high school student or the post-graduate scholar? Does a sixty year old find it as useful as, say, a thirty five year old mother with two children? Does it matter if the woman has advanced breast cancer, or has just undergone painful preliminary surgery? Is the information equally relevant, appropriate, 'simple' enough, or 'scientific' enough to cater for a diverse range of women and their specialised information needs? Research has detailed the constantly changing information needs of women as they proceed along the breast cancer trajectory (Luker *etal.*, 1996; Manaszewicz *et al.*, 2002), and the dissatisfaction with information provision (McGrath *et al.*, 1999; Girgis *et al.*, 2000; Jenkins *et al.*, 2001; Fallowfield, 2001). None of the existing resources or portals delivers customised information which meets the dynamic and diverse needs of the individual woman and her family. The woman with breast cancer is invariably viewed as a 'patient', a member of a uniform group, where 'one size fits all'. Factors such as age, life-style, location, ethnicity, education and reading levels are not addressed.

Breast cancer information resources online also emanate from a variety of organisations and institutions, and vary greatly in terms of quality, as well as accessibility and useability. If women and their families use this information to help them make critical health and life-style decisions, how sure can they be of its quality? How confident can they be of its provenance? How reliable is the information and how can the individual user assess this? Is the information from an authoritative source? Does it emanate from a source that has a vested interest in promoting one form of treatment over another? Is it from a mainstream, leading edge research or alternative medicine site? This type of contextual information or descriptive metadata about resources and their sources can enable users to judge factors such as reliability, quality, authoritativeness and authenticity for themselves, but it is not available to them via existing portals.

INTELLIGENT INFORMATION PORTALS

Christensen and Griffiths (2000) link the Internet's rapid growth to its capacity to meet the need for information to be accessible irrespective of location, to disseminate information quickly and regularly updated, and to provide users with access to a far wider range of information than would otherwise be possible. However they also note: "These qualities can lead to negative outcomes through, for example, the fast dissemination of inaccurate information." (2000:976) Christensen and Griffiths (2000) identify information overload and poorly organised information sites as particular problems in the health care area, noting that search engines, whilst helpful in locating masses of relevant information, have a problem with "retrieval precision". They suggest that a response to the issues of information overload and poorly organised sites has been the development of portals: "These sites usually consist of a collection of specific content, indexed, and a local search engine together with links to other recommended sites. The usefulness of such portals still depends on the sites referenced and the quality of the attached search engine." (2000:976-977). A number of intelligent portals in the health care area are currently available. Two healthcare portals that provide searchable health information, WebMD and HealthCentral.com. Some of the portals provide users with the ability to personalise their Web interactions: "Providing personalized views for individual users is one of the major advantages to the deployment of a web portal. Personalization is achieved through the creation of personal profiles containing user information and preferences. Portal access may be tailored by user preferences, need, security level and access authorization." (Murray, 2002:1881)

Most of the very limited reported research on intelligent portals focuses on improved search facilities (White 2000). In the case of commercial sites such as Amazon.com, current portal technology enables the development of profiles of users based on past use, to assist with future searches. One intelligent portal, *Health Smart Library*,

(http://www.hsl.wisc.edu/staff/web_team/health_smart.cfm) seeks to provide relevant information for health professionals, sorted by research interest and the particular branch of medicine.

The research reported in this paper envisages an intelligent portal serving multiple purposes, including the delivery of tailored, better-targeted and reliable medical, health care and related information to users who are in the process of making critical health and life-style decisions. The intelligent portal will improve the structure and manage the quantity of information presented. It will also provide the user with data about the authority, quality, and provenance of the information accessed, so that users can make their own judgments as to its reliability. It will more precisely meet the information needs of the users and provide information in a more timely manner, which can potentially help solve critical life problems. Support for decision-making and related quality and reliability issues are critical aspects of the current project. The intelligent portal will be designed to deal with this requirement, as well as with requirements relating to relevance, accessibility, and usability. Satisfying information needs to support decision making is concerned with providing timely access to relevant resource content *as well as* rich contextual information about the resources.

THE BCKONLINE PROJECT

The BCKOnline project, *An Intelligent User Sensitive Portal to Breast Cancer Knowledge Online,* aims to address the range of issues raised above. It is a collaborative, multidisciplinary research study funded by an Australian Research Council Linkage Grant, with matching funding from BreastCare Victoria – an initiative of the Victorian Department of Human Services – and the Breast Cancer Action Group, Victoria (BCAG).

The BCKOnline project consists of the following components (see Figure 1):

Phase 1 An extensive field study and user needs analysis leading to the development of context-rich user profiles.

Phase 2 Identification, assessment, and 'quality rating' of breast cancer information resources in accordance with evidence-based protocols and 'best practice' principles of web design.

Phase 3 Description of breast cancer information resources with reference to the outcomes of the user needs analysis, including requirements for value-added information about provenance, authoritativeness, quality, reliability and conditions and possible cost of access. This phase will involve the development of a descriptive metadata schema to support user-aware resource description (metadata schemas define standardised elements to be used in resource description).

Phase 4 Development of architecture for an electronic information resource that includes an intelligent portal that provides a gateway to existing breast cancer information resources; a metadata repository of resource descriptions, and a knowledge repository of additional resources.

Phase 5 Building a prototype of the information resource that demonstrates how an intelligent portal can provide differentiated access by matching user profiles to user-aware resource descriptions. This phase will also involve interpretive analysis of the field study data to refine the information search characteristics to be used in the intelligent interface design. The portal will utilise complex sets of metadata, resource descriptions and user profiles derived from the rich picture of user needs and patterns of use that emerge from Phase 1.

Phase 6 Intensive testing of the prototype with reference to user needs and expectations as identified in the first phase. The evaluation will be conducted from two perspectives: whether the intelligent portal meets differential user needs, and the level of satisfaction with the new resource, including perceptions of the quality of decision-making resulting from its use.

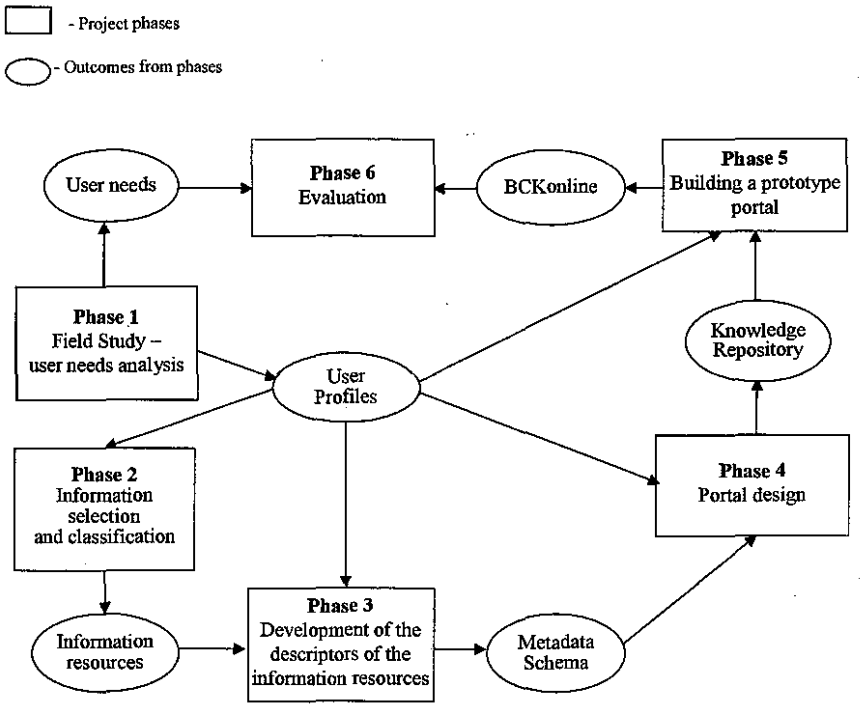


Figure 1: BCKOnline Project Structure

The rest of this paper reports on how the outcomes of the first three stages of the project, the identification of information needs, and relevant information resources, and the development of user-aware resource descriptions will be used in specifying and building the prototype of an intelligent information portal to better support the information and decision-making needs of Australian women with breast cancer. The researchers acknowledge the difficulties faced in the building and maintenance of such a portal, this stage has only recently commenced and we hope that in future papers we will have more details on the actual portal.

USER NEEDS ANALYSIS

Research method for field data collection and data analysis

Phase 1 of the project has been completed. It established the information needs, which an intelligent, user-sensitive portal might meet through in-depth interviews with 53 women who had experienced breast cancer. Participants lived in metropolitan, regional or rural Victoria or in rural NSW, and took part in either focus groups or individual interviews. A semi-structured interview schedule with a predetermined list of very broad questions was used for the interviews. The sample was a purposive one, selected to represent various age groups, disease stages, time since diagnosis, educational levels, marital status, urban and rural locations, and life styles. As Australia is a multicultural society, it was also considered essential that the voices of women from diverse ethnic backgrounds be heard, and the study involved participants from the Chinese, Italian, Greek, Lebanese and Aboriginal communities. Participants were recruited via breast cancer nurses in both the public and private sectors, and through facilitators of health care centres and breast cancer support groups. In addition, a separate focus group of eleven breast care nurses was held.

The gathering, coding and analysis of the qualitative data initially followed the grounded theory method, originally conceived by Glaser and Strauss (1967), but as outlined by Pidgeon and Henwood (1986). Analysis of data was a continuous process with the initial themes and categories, determined after the first few interviews, being continually reassessed and expanded as more data was collected. The data was also analysed using meta matrices as described by Miles and Huberman (1994). A matrix "... is essentially the 'crossing' of two lists, set up as rows and columns." (1994: 93). A database was developed and the data was classified according to key themes that emerged from the interviews. The textual data was then classified and entered into the matrix.

Research outcomes

The data gathered through the interviews and focus groups that is most significant to the development of the portal relates to the information participants found most useful; their preferred information formats; their overall impression of the 'quality' of the information; use of the Internet to locate breast cancer information; and the gaps they perceived in information provision. An overarching aim was to identify and define the "classes" of users, and the types of information that should be specifically targeted by an intelligent portal.

The audience

Women with breast cancer, like most users of the Internet, have diverse needs, come from a diversity of backgrounds, have reached different levels of education and are of various ages. Their information needs are also influenced by the stage of the disease, when they were notified they had the disease, their family arrangements, their culture, where they live, and the level of detail and degree of complexity of the information they require at any given time.

A comment from a divorced 46 year old mother living outside a large rural centre in Victoria illustrates the diversity of information needs of this group. When asked to comment on perceived gaps in current information provision, she said:

> *A list of surgeons. A list of oncologists. A list to say this doctor does one hundred plus a year. This doctor does three. Especially in rural areas, we might only have one doctor who does breasts, and ... some women don't know their options. There are other doctors who can do their surgery, who do breast surgery as a regular thing. And I think we need that... I think if you could go into [a] web site and know it was easy to look at: 'Okay, that's the area I want to go to. I don't need to look at all that stuff. That's all I'm interested in. That's where I'm going to go.' And then I switch off my computer and walk away. And it's not this overload of pamphlets. It's being able to choose the information you want at the time. What's right for you.*
>
> (Interviewee 23)

The words of this woman embody several of the major themes that emerged from the transcript and matrix analysis. Amongst those themes are the importance of timing and relevance of information materials; dangers of information overload; the need for 'practical' and localised information; and the potential for appropriate delivery mechanisms to empower the individual and hence contribute to improved decision-making and knowledge integration.

Current Internet information provision

There are a number of reasons why current provision of breast cancer information on the Internet, as well as in other formats, falls short of the ideal. On the one hand, there is a vast quantity of information available; on the other hand, some is of quite poor quality. These characteristics, together with the diverse and dynamic range of information needs, mentioned, means timely, relevant and reliable resources are not easy to find. The study confirmed that there are significant gaps in information provision, both on the Internet, and in other formats.

A number of key themes were identified through the interviews and focus groups. Those that relate specifically to the use and value of the Internet as an information source are discussed below. These point to the design requirements for an intelligent portal to better meet the information needs of women with breast cancer.

- Information quantity

Ball and Lillis (2001) note that 74% of Internet users in the United States have searched for health information. The Internet however exacerbates the problem of information overload. One woman (Interviewee 18) described this as an "avalanche". Many interviewees expressed similar concerns about there being too much information available through the Internet.

- Information quality

Coiera (2000) argues that the Internet's exponential growth and the information available, particularly low quality information, has resulted in users finding it increasingly difficult to locate accurate information particularly in the health area. Many of the participants are concerned about quality issues. Christensen and Griffith found in the area of mental health that: "One major concern is that consumers (and practitioners) will obtain inaccurate or potentially dangerous information." (2000:976) Their analysis of a number of mental health sites found information that was misinformed, could be misinterpreted and often did not have balance or provide information on treatments. Another study investigating breast cancer websites found that "less than one third of the sites identified references or sources for information cited at the site" (Goetz and Clarke, 2000:283) Concerns of accuracy and validity amongst the women in the study is reflected in the following comment:

> *I mean 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.*
>
> (Interviewee 13)

- Issues of relevance and timing

The need for relevant information was widely discussed by participants, often linked to issues of quantity and quality of information. The perceived relevance of information is frequently associated with differing needs at different stages of disease:

> *But I really found that a lot of the time the information that you get, until it suddenly is part of what you're going through, (is) not relevant and therefore... you have read a lot of information that you're not taking in. It's a process.*
>
> (Interviewee 3)

> *When you've got secondary cancer, it depends on what stage you're given the information, whether you're still in the shock of having the secondary cancer back when you're not expecting it to be there. And also, even if you're told you forget... the information...(that's)... given to you.*
>
> (Interviewee 14)

Information relevance also relates to the type of information women require. Some women want very detailed medical information while others want more basic information as the two following quotes illustrate:

> *I found, and that's because of my personality and the information I need, that I needed authoritative information with a lot of detail. I did like reading the more in-depth discussions from women who had experienced cancer because I need the two fold, both sides – the emotional and the factual. Not the brief little pamphlety stuff.*
>
> (Interviewee 8)

> *I went to the Internet at that stage. I didn't find much because you're really finding scientific medical sites and I'm not [wanting that].*
>
> (Interviewee 10)

There is also a problem for participants in not always knowing exactly what it is they want to know:

> *I've spent ages on the Internet wandering all around, looking for things... until I think very clearly what is the key word that I really want to know. And that's the same with asking questions that sometimes we just don't know. We know we want to know something, but we don't know how to get there.*
>
> (Interviewee 5)

Other themes that emerged included the need for information to be presented in a way that caters for a range of reading levels and format preferences. One woman found the visual element crucial to her decision making process:

> *Look, the most important thing for me was to go and speak to someone else and see someone else's reconstruction. As soon as I saw that reconstruction I was completely at peace about having it. .... The visual thing really helped me. I think that was very important in the reconstruction. Or knowing that I was going to have a mastectomy, what was I going to look like down the line?*
>
> (Interviewee 16)

- Information gaps

Despite the quantity of information available on the Internet many of the women commented on information gaps. For example one woman suggested the need for: *"A bibliography of different sources of information. Suggestions about where you could find extra information."* (Interviewee 8). She reflected that even on the Internet she had not had much success in looking for some of the things that she wanted.

Other gaps identified related to facilitative information, e.g. on travel, allowances and accommodation near treatment centres. During part of a discussion focused on the difficulty of discovering and accessing local services, one woman commented:

> *If it's on the web...it should be easy to find and it should be a whole list of all the allowances and grants and the eligibility and how you get it. It's got to be a hell of a lot easier than relying on people to tell you (by) word of mouth.*
>
> (Interviewee 23)

The women also expressed a need for better links into other resources, for example:

> *I wonder if we could link into the Breast Cancer Network Australia [a national advocacy group]. If they're trying to get [a] support database, it will be wonderful to be able to logon and see, if you're a lady living way way out in Woop Woop with no access to a support group, to know that there is a support group with interests very similar to mine. It would be fantastic to have that.*
>
> (Interviewee 23)

The need for a tailored portal to serve the needs of women with breast cancer for relevant and reliable information is encapsulated in the following comment:

> *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)

The data collected and analysed in Phase 1 of the project is being used to develop a rich picture of the patterns of user needs and profiles of "classes" of users. This will feed into the identification of relevant resources and their description in user-aware ways, and into the design of search strategies for the intelligent portal.

USER AWARE RESOURCE DESCRIPTION

In Phase 2 of the project, breast cancer information resources are being identified, assessed, and quality rated. Gaps in information provision are also being identified. Relevant resources will then be described with reference to the outcomes of the user needs analysis and profiling described above. Criteria established by organisations such as DISCERN (http://www.discern.org.uk/), Cancer*Index*

(http://www.cancerindex.org/clinks18.htm); MITRETEK (http://hitiweb.mitretek.org/iq/), BIOME (http://biome.ac.uk/guidelines/eval/factors.html), and the JAMA guide to 'Quality on the Net' are being used to assess and quality rate the resources, taking into account factors such as accuracy, source, authorship, commercial affiliations and extent of evidence-based protocols. Information resources are also being evaluated according to defined criteria, which address issues such as reading, levels, intended audience, use of medical terminology, and suitability for the differing needs of the target audience for the portal. These criteria are being specified using the results of the user needs analysis, and include factors such as educational levels, socio-economic backgrounds, stage of treatment, ethnicity, age group and residential location in city or rural areas.

In Phase 3, the breast cancer information resources identified, assessed and quality rated in Phase 2 will be described in ways which enable the portal to match user needs to highly relevant information resources, and to provide value-added information to the user about the resource being accessed, e.g. its provenance, authority, authoritativeness, quality, conditions and costs associated with access – if applicable. This will be supported by the extension of existing resource discovery metadata schema to meet the requirements of user-aware resource description.

Use of metadata

The breast cancer information resources will be described using a set of standardised descriptive elements. Specification of an appropriate metadata schema, which identifies in a standardised way the elements needed to describe a resource, will be a critical part of this component. Evaluation of the potential of existing resource discovery metadata schemas to provide user-aware resource descriptions and information about the quality and reliability of resource is being undertaken. The international de facto standard for describing documents on the web, the Dublin Core (http://purl.oclc.org/metadata/dublin_core), does not address the issue of the target audience for the resource described, and has a limited capacity to provide information that would enable users to judge quality and reliability.

The Australian Government Locator Service (AGLS) is based on and extends the Dublin Core set of descriptive metadata elements (National Archives of Australia, 1999). It was originally developed for application in Australian government contexts, and is being redeveloped as an Australian national standard. As the AGLS is about to become the national standard for resource discovery metadata in Australia, and provides a more extensive set of metadata elements than the Dublin Core, including an Audience Element, the AGLS metadata schema is being used as the basis for resource description in this project. However, as it currently has a limited capacity to describe the target audiences for the resource, the project will extend and customise this aspect of AGLS to enable the description of resources in ways that are more sensitive to the needs of target audiences or classes of individual users. New metadata elements will be defined with reference to the user profiles and patterns of use emerging from Phase 1. The AGLS may also need to be extended to deal with the requirements relating to reliability and quality. Schema analysis, metadata modelling, concept mapping of metadata schema and standards, and empirical instantiation (which populates models with examples) will then be used to develop the semantic structure for the metadata repository (McKemmish, 1999).

New methods will be developed to translate the outcomes of the user needs analysis, user profiling and resource assessment into specifications for metadata schema requirements for user-sensitive resource descriptions. The metadata repository will be designed, built and populated with resource descriptions as a component of the intelligent portal.

DESIGNING AN INTELLIGENT USER SENSITIVE INFORMATION PORTAL

The focus of the project is on delivering resources in a customised way to meet the individual information and decision support needs of users from diverse backgrounds. The work includes the development of a metadata schema which supports resource description that is sensitive to the diverse and changing information and the decision support needs of a target audience, and designing an intelligent portal which can use dynamic, context-rich user profiles, and user-aware resource descriptions to provide timely access to relevant online resources. The intelligent information portal will be designed to:

- Enable the user to control the flow and 'content' (hence relevance) of information i.e. if only 'scientific medical articles' are desired, then the descriptors will identify this;
- Offer the user alternatives as to format ie. aural, visual, textual - again by matching descriptors and profiles, so that the user may decide to refer to visual whilst reading etc. (as in www.dipex.org);
- Presenting a 'hierarchy' of subject matter which runs simultaneously along user profiles and descriptors ie. the continuum of disease stage may be the basis, but then this is overlaid with specific user profile material;
- Precision is paramount rather than recall - results in less repetitive material etc;
- Assist the user in making judgments about the quality and authoritativeness of the source of the information based on the metadata attached to it.

Personalisation in a context of portal technology is usually treated as "adaptation of the portal to a user's preferences. Only those documents and news are shown that are related to topics which have been pre-selected by the user" (Allweyer, 1999). However, we intend to extend this understanding based on the preliminary exploration of the users needs. In addressing the issues of information relevance and stage of disease for example, it is more important to avoid sending irrelevant material that may adversely affect the user by influencing their mental state and causing unnecessary stress.

The other attractive feature of the web-based user sensitive information portal is an opportunity of anonymous access to some stored personal stories available through an analogical search engine. Intelligent agents can be set up providing a user with some interesting documents, based on her previous search and browsing activities.

Effective communication with the relevant communities and supporting groups is a very important component of information seeking activity for women with breast cancer and their families, particularly for those outside metropolitan areas. There are many medical websites incorporating discussion and chat-line facilities that link people with those who have or have had similar problems (Breast Cancer Action Nova Scotia, 2002). Communication facilities and mailing lists generated through the portal can be used to identify and support communities of interest and as channels for targeted broadcasting of selected information.

There was one issue of concern identified with the use of enterprise portals: some of the information which the users filtered out because they judged to be irrelevant was in fact information which the information providers considered critical to the integrity of the internal processes (The Delphi Group, 2000). This issue is less critical in the context of this project, however some attention will be paid to researching the minimum amount of information that should remain after filtering to minimise a risk of ill-informed decision making.

Proposed Portal Functionality

The proposed portal is envisaged as playing the role of a gateway to information about breast cancer. The concept of an intelligent portal offers the opportunity to explore a range of functionalities including:

- Together with the original website links, an archived collection of information resources can be stored and maintained on a local server as a part of the knowledge repository.
- A set of references to official publications produced by medical and government authorities can be centrally maintained as a part of knowledge repository.
- The portal will provide an alternative way for distributing newsletters and other periodical publications by using "push" technology-like functions.
- With the permission of copyright owners, the provision of 'deconstructed' print materials, allowing users to focus on specific subject domains rather than an entire publication.
- A variety of 'medical' sources including research journals, photographic displays relating to the most current results in breast cancer research could be monitored

by the 'owners' of the portal as sources of information which can be adapted to meet the needs of a range of audiences.

- Published reviews of literature on breast cancer can also be made available through the portal.
- The portal may periodically commission and/ or provide targeted review on a particular topic which emerges from the frequently asked questions list.
- Information about support groups will be collated; it is envisaged that these groups will see the BCKOnline portal as a key avenue for the dissemination of information about their activities.
- List of relevant specialists with their specific expertise will be compiled and may be made available on request.
- The portal will allow users to select the 'depth' and format (textual or pictorial only, auditory, etc) of the required material; (formatting options will obviously depend on the limitations of the user's technical environment, for example limitations of speed and restrictions on the volume of downloaded data).
- Materials and sites in foreign languages should be provided where available to cater for the needs of the ethnic groups, as well as to contact details for accredited translators and interpreters.
- Through the communication facilities of the portal, people with similar interests and backgrounds would be able to register their interest and be put in touch with each other.
- A bulletin-board facility providing brief information about the threads of topics with an ability to get more information if desired; this information service can be provided and maintained by the future portal "owners" and supported at the knowledge repository level.
- An electronic glossary with hyperlinks to examples and reference material could be compiled and made available as a part of a breast cancer knowledge repository (this addresses one of the problems with any specialist domain, and the medical field in particular).
- A simple "how-to" repository of hints and advice on processes associated with getting access to government information and forms, along with online forms where possible.
- The portal should be seen as a first reference point for novice users, offering various levels of information coverage, and helping to building their self confidence (by tracing login information the portal should be able to differentiate between new users and experienced users).
- In accordance with the best practice of the third generation of knowledge management (Snowden, 2002) experiential knowledge is best represented in a form of narrative which the knowledge seeker can easily relate to due to the richness of the recorded context; in this sense women's stories can be made available on-line and can be used as a mechanism for matching user profiles and suitable information resources.

It is envisaged that breast care nurses and possibly general practitioners will use the password-protected areas of the portal, in particular evidence-based 'specialist' bulletin-boards, to access the most up-to-date information on clinical trial results. The above list of potential functionalities includes both content elements and technological features and it will probably be beyond the scope of the project to achieve them all. The aim is to develop solid and convincing evidence that an intelligent on-line knowledge resource for the breast cancer community is implementable and worthwhile in an operational environment so that it can be adopted, maintained and further developed by a suitable 'owner'.

CONCLUSION

The availability of quality on-line information for supporting critical decision-making still represents a problem rather than an opportunity for women with breast cancer and their families. There are many reasons for this including poor control of the web site content, the

inability of search engines to address the varying needs of information seekers and the information overload which results from search engines maximising recall rather than precision. In specific subject areas such as this one a level of personal knowledge and involvement with the topic compounds the problem. A 'portal' is a technological solution which makes it possible to match the needs of a targeted audience by channelling specifically selected information in a 'just in time' fashion. According to Birkbeck College, University of London Glossary of Terms (2001), 'portal' can be defined as "a World Wide Web site that is or proposes to be a major starting site for users when they get connected to the Web or that users tend to visit as an anchor site". This starting point can potentially provide a 'window of opportunity' for someone with particular needs and expectations when searching for information in an area of critical decision-making.

Enterprise portals are increasingly used in organisations "to allow targeted audiences to access and interact with relevant information, applications and business processes" (Smith and Phifer, 2002). Portals addressing the needs of social groups are less popular. However, there is a recognised need to address the information seeking problems of the broader community, especially when some level of differentiation can be achieved through using intelligent portals functionality.

This paper describes a two-year research project, which aims at building a gateway to knowledge on line complemented by a knowledge repository including a metadata repository and selected additional resources not currently accessible on line. The project is a collaborative effort undertaken by a group of researchers with a multidisciplinary approach to information seeking and provision. The project started with a detailed user needs analysis, then proceeded with classification of the information resources and development of specially created metadata schema, which will provide a mechanism for implementing an intelligent filter for the breast cancer information portal. This portal aims to match the expectations of patients with breast cancer, their family and friends, helping them find what they need to know when they need it and in a form, which most effectively gives them actionable, empowering knowledge.

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