

Patient-Centred Approach to Focusing Online Health Information Search Results

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Abstract. Over recent years the amount of health related information available via the Internet has greatly increased, and is being provided by a vast array of information providers, from government-owned public bodies to charities and to individuals publishing based on their experiences. This paper addresses the two main challenges to using this information: information overload and information quality. It also proposes a unique solution to these problems that can be used across all medical conditions, by facilitating the personalisation of online information searches, and enabling patient access to a proposed common EPRS in Wales.

Keywords: Information Quality, Information Overload, Internet Searching, EPRS, Personal Health Gateway

1. Introduction

The last decade has seen an increased demand to improve the availability of health information provided to patients and their carers. This is mainly due to:

- Changing the healthcare delivery model to a '*patient centred approach*' [24] whereby healthcare provision is tailored around an individual patient's needs to enable people to remain in control of their treatment and live independent lives.
- The recent advances in technology, empowering patients by enabling access to health information where time and geographical location no longer limit access to information, in particular the availability of the World Wide Web [1]. As an American study reveals:

"Fifty-two million American adults, or 55% of those with Internet access, have used the Web to get health or medical information. A

great many are using the Web to gather information on behalf of family and friends” Pew Internet (2006) [37]

In the UK, a wide variety of online information sources are available via the Internet that provides a vast amount of information freely. This includes:

- Government-controlled web sites that provide general health information for the public such as the National Electronic Library for Health (NELH) [30] and NHS Direct Online [32];
- Private health providers detailing their services, such as the British United Provident Association (BUPA) [10] that provides an A-Z index for information on healthy living, conditions and treatments;
- Non Government Organisations (NGO) such as the British Heart Foundation (BHF) [7] and Macmillan Cancer Support (MCS) [26]. These typically provide information to support patients in achieving the best possible quality of life by providing, for example, subject-specific information, details on medication and available therapies, and online support forums;
- Individuals (professional and/or interested amateurs) publishing knowledge online for use by others, e.g. Will’s World [25];
- Business sectors potentially advertising their products, such as GlaxoSmithKline [16] providing positively-slanted information about their prescription drugs, and Imperial Tobacco publishing comments on smoking and health [21];
- Blogs, online diaries and online discussion forums, where individuals can discuss any topic they wish, including healthcare issues, and receive comments back from others, such as the web site of BBC journalist Ivan Noble that described his experience of living with a brain tumour and explained how searching the net for information on his condition gave him a ‘severe fright’ [34].

Although plentiful, a number of challenges still hinder patients and their carers when searching for high quality, reliable health information via the Internet.

“It is wonderful that so much information is available and that patients can be as well informed as they want to be. But it is very difficult to filter that information. It is not possible to start search the net and hope to see only encouraging news” Noble (2002) [33].

Our paper addresses the two main challenges facing those who search for information online, that of information overload and information quality, and presents a generic system that will overcome these obstacles. It also highlights other challenges, such as information security, and proposes potential solutions.

In this paper we present the pilot stage of the Personal Health Gateway (PHG) project. The first stage of this project is to develop an advanced Internet search facility to combat the issues of information overload and information quality, by enabling individuals to personalise their information search requirements based on, for example, the type of information they require (such as potential side-effects of prescribed medication), their current medical condition and medication, stage of

illness, support needs, and prior level of medical knowledge. These, plus many other factors, will influence the type of information the individual requires and thus can be used to focus Internet search results to increase the perceived quality of the obtained information.

Once completed, the second phase of this project plans to develop a link to a common electronic patient record, as proposed for Wales in [3]. Providing patients with access to their electronic record will enable them to gain a fuller understanding of their condition, and use this information as a basis for online searching.

The remainder of this paper is organised as follows. Section 2 discusses the two main challenges to information searching on the internet, those of information overload and information quality. Section 3 then introduces our proposed approach to combating these problems: the Personal Health Gateway. This is a generic approach that empowers patients, their families and their carers by encouraging patient ownership of their health information and Internet searching preference criteria, related to any medical condition. In section 4 the paper then presents the future development for this project, including linking to the proposed common Electronic Patient Record System (EPRS) in Wales [3] and the development of Travelling Health Companion.

2. Internet Search Challenges

When diagnosed with a condition, for example cancer, patients use the internet either directly or via friends and family for a number of reasons. These reasons include, but are not limited to:

- To interpret symptoms
- To obtain second opinions
- To make sense of medical terminology
- To tackle feelings of isolation
- To develop social connections
- To identify questions for their doctor
- To find alternative and complementary therapies for their condition [38]

As stated in section 1, the two main challenges to finding this and other information on the Internet are information overload and information quality. This section describes these two issues in further detail.

2.1 Information Overload

“The term information overload describes situations in which the individual is no longer able to integrate new information for decision-making, due to the great amount of information he or she is exposed to. He or she can no longer productively use the quantity of information in

the available time scale. In consequence, decision quality, efficiency, and even well-being may be reduced” Eppler (2001) [13].

As the volume of available information increases the information consumer begins to suffer from information overload [23, 31, 40], where it becomes increasingly difficult, or even impossible, to find the information they require amongst that which is available.

For example when conducting a standard Internet search using an engine such as Google [14, 35] for a simple sentence such as ‘*cancer support group*’, over 50 million results are returned. The required information may be included within this result set, but this often also includes a large number of irrelevant information. Consequently, it becomes impossible to manually search through them all to identify the relevant subset. The information overload problem, also known as ‘cognitive overload’ or ‘information fatigue’, is compounded when the information is also of dubious quality, and is presented in a diverse array of formats (e.g. text vs graphical, precise vs vague, local vs international standard, professional medical vs amateur produced information, etc). This multidimensional view of information overload is shown in Figure 1.

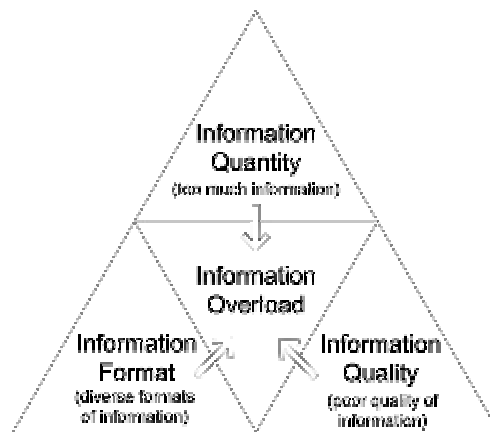


Fig. 1. Information overload as a three-dimensional problem [19]

Although the Internet makes an immense amount of information available to individuals and patients, information overload can result in a number of difficulties [41]. For example:

- Failing to hear about latest developments regarding treatments for their illness;
- Obtaining incomplete or incorrect details on the side-effects of their medication;
- Failing to find online descriptions of the experiences of others suffering from the same condition;
- Being unable to locate local support groups and thus missing out on potentially life-changing experiences;

- Finding condition-specific information, but in a form that requires prior medical knowledge in order to comprehend its contents, thus failing to find required information due to the use of specialised terminology.

This problem is not specific to patients and their carers. It also impacts the information processing effectiveness of medical professionals, affecting, for example, their ability to keep informed of the latest medical developments [18].

2.2 Information Quality

Quality information is typically defined as that which is ‘fit for use’ [22]. This implies that the quality of some piece of information is dependent upon the use to which it is being applied. So, what may be considered as being high quality information in one situation may not be perceived as such in another. This section discusses the issue of quality information on the Internet, focusing on the two issues of the differences between individual information searchers and the variety of information providers. It concludes with a discussion on Google and the PageRank algorithm, which goes some way towards tackling this issue.

2.2.1 Individual Differences

“The notion of information quality depends on the actual use of information. What may be considered good quality information in one case (for a specific application or user) may not be sufficient in another case” Huang et al (1999) [20].

The quality of internet search results, as perceived by the searcher, will vary for a number of reasons. These reasons include, but are not limited to, the following:

- Prior knowledge of the topic or medical condition being investigated;
- Expectations of the individual – information perceived as being of high quality by one individual may be perceived as poor quality by another;
- Bias of the information producer (independent health professional or organisation, local health authority, drug company, pharmacy)
- Current information requirements, such as whether peer-reviewed scientific information is required (e.g. an article from the BMJ [9]) or a non-technical overview of a specific medical condition (e.g. explanation of heart disease from the British Heart Foundation [7]).

Due to the unique nature of every individual, a single search method that assumes all people are the same will fail to meet every person’s information needs.

2.2.2 Varying Quality Amongst Information Providers

“Information quality is the main discriminator of data and data sources on the web” Naumann (2001) [28].

Information obtained from different sources will typically be of differing levels of quality. When searching for information online sites can often contain out-of-date or unavailable information [39], incorrect information [4, 5], or provide access to people

selling substances not intended for general use, such as drugs with little or no safety instructions [5, 6]. This is partly due to the lack of controlling body, and that available information is constantly changing within such a fluid environment. Sites may also provide access to unscrupulous sources selling prescription-only drugs without requesting a prescription, often resulting in damaged, incomplete, incorrectly packaged and even incorrect orders being delivered to their customers [17]. Previous studies in the health-care domain have highlighted the worryingly poor-quality of some online information providers, and the detrimental effect this can potentially have on consumers [12]. This lack of quality becomes a concern when people believe what they see with little or no regard as to its accuracy [15].

2.2.3 Google and the PageRank Algorithm

Google's PageRank algorithm [36] goes some way towards improving the quality of Internet search results, by ranking highly those web sites that are referenced by many other sites, with more emphasis on links from sites which are themselves considered as being of high quality. This in effect incorporates peer reviews of web sites from other site developers. Alongside this, Google's ranking method also takes into account user feedback for each site and favours sites that are frequently updated.

Google's method for ranking the relevance of web pages retrieved from an information search has made it one of the most popular Internet search engines. However, the main problem with this, and other, online search services is the assumption that all individuals have the same information requirements. Two users querying an online search system at the same time, entering the same keywords, will receive identical search results, yet they are likely to have different opinions regarding the quality of that information due to their different opinions, needs, prior knowledge, etc. A one-method-suits-all approach cannot meet the needs of all individuals.

Our proposed approach builds on search technologies developed by such organisations as Google by providing additional search personalisation facilities, enabling individuals to explicitly state their current search preferences, and resulting in a focused set of Internet search results.

3. Personal Health Gateway

To combat the aforementioned issues of information overload and information quality when currently searching for health information on the Internet we propose an online Personal Health Gateway to assist individuals in finding the best available information based on their current information requirements.

In previous work we showed that it is possible to focus information search results, within a closed-world environment, based on varying personal information preferences [11]. This project builds on that work by using the developed techniques within an open environment – the Internet. By providing the information searcher with a method for customising their search by stating their current information

preferences the results of an Internet search conducted, for example, using Google, can be focused based on their requirements. The probability of these results meeting their current need is thereby increased, resulting in a perceived increase in search quality.

Information Search

Search term

UK Worldwide

Search Options

Selecting one or more of the following options will help in focusing the results of your search based on your current needs.

<input type="checkbox"/> Condition overview	<input type="checkbox"/> Medication information
<input type="checkbox"/> Detailed condition information	<input checked="" type="checkbox"/> Medication side-effects
<input type="checkbox"/> Individual experiences	<input type="checkbox"/> News articles
<input type="checkbox"/> Support groups	<input type="checkbox"/> Health authority policies
<input checked="" type="checkbox"/> Long-term prognosis	<input type="checkbox"/> Information for carers
<input checked="" type="checkbox"/> Quality of life	<input type="checkbox"/> Alternative therapies

Fig. 2. Prototype information search web interface

The prototype information search web interface is shown in Figure 2. The user can currently enter some search term, or terms, and conduct a standard Internet search using that term alone. This does not, however, improve on the currently available search systems. The first stage of this project will therefore concentrate on providing a facility to allow the user to focus their search by selecting from a number of factors, highlighting their information requirements, such as illustrated in Figure 2. These preferences will be used during the search process to ensure that the returned result set ordering prioritises information currently required rather than relying on the user to manually sift through a large number of potential results to find those that are suitable. Initially experimentation will be conducted offline on a static data set, obtained from currently available online information providers, in order to demonstrate the feasibility of such a system. Once completed the search facility will be opened up to live Internet data and be made accessible to all potential users.

4. Future work

In section 3 we introduced our prototype web interface for our proposed search facility, to facilitate the personalisation of information search requests in order to focus the returned result set based on current individual requirements. Further development is required before this system can be launched, and used by patients and others wishing to discover health-related information via the Internet.

However, a number of other further developments are planned for investigation within this current project. In this section we briefly introduce these planned developments to the Personal Health Gateway.

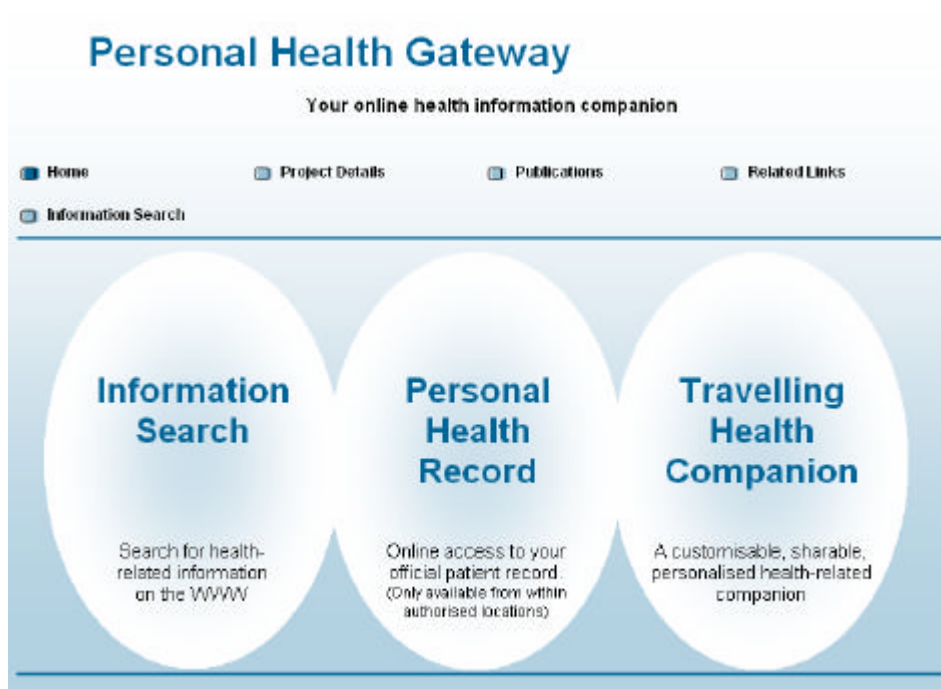


Fig. 3. Future developments for PHG

4.1 Personal Health Record

Figure 3 illustrates the additional features to be incorporated into PHG. Section 3 discussed the Information Search facility currently being developed. The second aspect to PHG is intended to provide patients with access to their personal electronic patient record. Previous work conducted with Velindre NHS Trust, the South East Wales cancer centre, proposed the development of a common Electronic Patient Record System (EPRS) for Wales with the aim of recording and supplying required

information to all care sectors according to the needs and working practices of clinicians in each care sector [3]. The legal right for each patient to access their health records is currently rarely exercised. By providing access to his proposed EPRS patients will be able to freely access this information, initially only via designated locations such as NHS hospitals and GP surgeries. This ensures security of personal, potentially sensitive, information and will alleviate patient concerns regarding the transport of secure information across the WWW.

Medical information may not be comprehensible to all patients due to their lack of medical expertise. Both the PatientKB [2] and PIGLET [8] projects are starting to tackle this by using ontologies (in the former) and artificial intelligence techniques (in the latter) to generate simple explanations of medical terms to facilitate patient understanding of their condition. The results of these and other projects in this area thus need to be considered and incorporated into the proposed PHG in order to empower patients by increasing accessibility of their personal health record.

4.2 Travelling Health Companion

The third facility to be developed during the PHG project is a Travelling Health Companion (THC). A personal ID and password will allow access to this section via a web browser, from any location. Within this section each user can develop a personal profile detailing current health conditions and medications, personal notes made as a result of a session with a clinician or therapist, notes for their next clinical appointment (such as questions they wish to ask), results of previous Internet searches and links to potentially useful online information. The THC will also enable the patient to create a personal health overview to share with others, such as family or carers.

4.3 Further Developments

A number of other developments are also proposed for future inclusion in the PHG project. These include, but are not restricted to, the following:

- The incorporation of automatic quality evaluations of online information to ensure individuals receive accurate, reliable information over poor quality web resources, using techniques developed in such projects as [27] and [29].
- The development of a dynamic ontology to describe, and learn from experience, the perceived information requirements of PHG users. For example, one default set of search preferences can be provided to a patient newly diagnosed with eczema, with another set presented to a patient with long-standing asthma.
- Using diagnosis ontologies to assist patients and further focus their information searches [1].
- Linking PHG to the proposed common Electronic Patient Record System for Wales [3].

- Investigation into a patient anonymisation facility, enabling individuals to create an untraceable personal profile that can be used to participate in online discussions, including the posting of potentially sensitive information. Due to the ease in which individuals can often be traced from online discussion forum postings, some may be dissuaded from seeking the help and support that could potentially improve their situation, either physically or emotionally. For example, a patient recently diagnosed with HIV may not wish to partake in an online support group in case their employer finds out about their condition.
- Investigation into the security issues relating to the transfer of personal health details across the Internet. Individuals may be reluctant to access their health records via a web browser if they have any doubt regarding its security.
- Examination into the potential for incorporating other developments, such as those made during the PIGLET [8] project, into the PHG.

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