Health Information on the Internet: Retrieval and Assessment Strategies for Consumers

Margaret Wohlers

The Internet is only one source of health information for consumers. It is however the fastest growing source of health information with over five million websites worldwide, of which 100,000 are health related. The complexities of information seeking behaviour, barriers to access and the many sources of health information other than the Internet are documented by the Twyford Report and are not covered here. There does however appear to be a need for a guide for consumers on how to find health information on the Internet and evaluate its quality and the quality of the website providing the information. This article attempts to meet this need.

The time has never been better for consumers to build partnerships with their health service providers. Consumers now potentially have access to the same information health professionals use to make decisions in consultation with their patients. In addition, the National Expert Group on Safety and Quality in Australian Health Care has created a policy climate to enable consumers to participate in all aspects of service delivery including strategies to improve the quality and accessibility of consumer health information.

Like all change involving social systems, the Internet is made up of complex and interdependent parts with development and adjustment happening as it matures. One of the reasons for the unprecedented growth of a medium is that the Internet is a generic communication medium with protocols and standards being developed to ensure anyone and everyone can both access and/or provide information - whether for profit, as policy or as a way of delivering services and entertainment.

The Process

The following flow chart is designed to help consumers work through a step-by-step process to find health information on the Internet relevant to their specific needs. This is followed by a detailed look at each step.

Figure 1.

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<th>Step 1.</th>
<th>Am I clear about what category of information I need?</th>
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Am I Clear About what Category of Information I Need?

Irrespective of format, health information tends to fall into one or more of the following categories.
1. **Health Promotion**

Health promotion arose from a recognition that the determinants of ill health were often to be found in social, economic and environmental conditions and was defined by the World Health Organisation in 1984 …*the process of enabling people to increase control over, and to improve, their health*. Government’s commitment to consumers becoming informed and participating in decisions about their own health care is demonstrated by the number of websites now available free to consumers with a focus on prevention, wellness and the informed consumer. These sites have strict quality controls in place with regard to technical issues (for visually and physically impaired consumers) and quality of content. They are known as portals or gateways because they do not provide content themselves but provide instead links to sites that have been assessed according to particular quality criteria. Because they are a one-stop-shop for a wide range of information and quality controlled, they are the best place for consumers to start their search. Examples of these sites are:

- [http://www.healthinsite.gov.au](http://www.healthinsite.gov.au) This site is funded by Commonwealth Department of Health and Aged Care and provides information for consumers ranging from daily health needs to information clustered around life events.

- [http://www.healthyageing.com.au](http://www.healthyageing.com.au) This site is jointly funded by Department of Human Services Victoria and New South Wales Health. Its purpose is to assist older people (and their practitioners) to find reliable, current and useful information.

- [http://www.betterhealth.vic.gov.au](http://www.betterhealth.vic.gov.au). This site is similar to HealthInsitie but funded by Department of Human Services Victoria. Information is divided into categories of healthy living, health conditions, local health services, support and advice, and life events.

All web sites mentioned above contain links to networks of services.

2. **Health Conditions**

This category usually relates to basic information about a medical condition, what causes it and how *sufferers* can help prevent its re-occurrence. However, consumers need to be alert to the differing perspectives and/or biases of information providers. Perspectives include the medical model, the social model and the feminist/social model each starting from a different place or belief. Apart from these differences, the health conditions category of information overlaps with the health promotion category - both of which are well covered by the web sites mentioned.

Typical sites providing health condition information are Arthritis Victoria [http://www.arthritisvic.org.au](http://www.arthritisvic.org.au) and Asthma Victoria ([www.asthma.org.au](http://www.asthma.org.au)) both of which make an effort to balance their perspectives by providing information about the scope of a particular condition based on medical research including symptoms and treatment options.

New *unproven* remedies are included in some sites, for example, Arthritis Australia, plus consumers are invited to share their experiences and alternative thoughts with other consumers. However, it will be interesting to see whether those views which challenge dominant perspectives will be *censored* by the webmaster or whether they also will be available to consumers visiting the site. For example, Byrne mentions in her paper, *Consumer Concerns Re Cochrane Review*, trying for many years to get the medical profession to consider the accumulating evidence that the physical problems are the end result of a very complex psychoneuroimmunological reaction activated by stress. By way of a contrast, Women’s Health Victoria ([http://whv.org.au](http://whv.org.au)) is a provider of health information which aims
to balance the varying perspectives through its commitment to ensuring the process of information development and provision includes consumer experiences and voices.

3. **Choice and Participation in Treatment Options**

The Task Force on Quality in Australian Health Care in 1996 determined that consumers want information about their health care based on the best available evidence. According to Eysenbach’s article in the BRITISH MEDICAL JOURNAL, Health professionals believe evidence-based medicine to be the answer to consumers who get *lost in a stew of information* or becoming a *hyperhypochondriac*. And who confront doctors with anecdotes from the Internet.

There are a number of problems with evidence-based health information for consumers. At a practical level, consumers do not have access to evidence-based resources, most typically, the Cochrane Library. This electronic library can be purchased in CD ROM format or direct Internet subscription. In rare cases it is available for consumers to use in some special libraries. Consumers cannot therefore access it free on the Internet and its purchase by individual consumers could not be justified. Consumer groups need to keep up the pressure to change this situation and make the Cochrane Library more accessible for consumers.

A common criticism of the Cochrane based information is that it is concerned with accumulating proof of effectiveness of clinical interventions based on clinical trials, meta-analysis and systematic reviews. According to Perkin et al in EVIDENCE-BASED HEALTH PROMOTION, *It is basically a bio-medical model, in which the ultimate effectiveness of interventions is expressed in hard outcomes such as mortality and morbidity, and behavioural outcomes*. Until consumers have input into its relevance, and until evidence-based health promotion is given equal weight, the Cochrane Library will remain a tool for the medical professions.

4. **Health Services**

Information about health services near to where you live or work is an important part of the picture. For example, the Victorian government website http://www.vic.gov.au provides information about a range of services available throughout Victoria including services to help older people remain independent and safe in their own homes.

Eysenbach in his article in the BRITISH MEDICAL JOURNAL, categorises health information available on the Internet as belonging to either:

- (tele)medicine, defined as diagnostic and curative medicine. Its main target audience is the medical profession and it is usually provided by professional health organisations (e.g. British Medical Association) which publish and disseminate research based information in both print and electronic format, or
- (cyber)medicine, defined as preventive medicine and public health. It is usually published by community based, non-profit organisations who work from the social model of health, providing a balance and challenge to the, until now, dominant medical model.
- (ecom)medicine, I define this as health information readily accessible on the Internet but which is profit motivated and commonly lacks standards, quality control, a scientific base and evidence that consumers were involved in its development.
Do I Know Which Search Software to Use?

There are many and varied search engines (also known as software search tools) specifically designed for searching the Internet. Search engines are software programmes designed to help users find what they are looking for. A comprehensive list of search engines in the area of health and social care, is available from the King’s Fund web site at http://www.kingsfund.org.uk/elibrary/html/links.htm More generalist search engines are listed in the following chart. These search engines are readily available free from the Internet. Some search engines are geared to automatically pick up sites containing specific keywords while some of the newer ones have strategies for quality control where people busily index (choose search terms that describe) millions of web pages throughout the world and make these terms available to you – the searcher. Each has a particular focus, purpose and strength with the more recent ones trying to address issues of quality of the sites they choose to index. None are entirely dedicated to linking consumers to health information.

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<tr>
<th>Search engine URL</th>
<th>Strengths</th>
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<tr>
<td><a href="http://www.altavista.com">http://www.altavista.com</a></td>
<td>Web searches, News groups and topic directory grouped into categories for easy selection. Includes advanced search form for search term combination</td>
</tr>
<tr>
<td><a href="http://www.excite.com">http://www.excite.com</a></td>
<td>Web searches, topic directory, News groups, Articles from 300 publications, Travel guides. Strength lies in its use of plain English search terms</td>
</tr>
<tr>
<td><a href="http://www.hotbot.com">http://www.hotbot.com</a></td>
<td>Web searches, Topic directory, Online shopping directory, News groups. Provides simple point and click search features.</td>
</tr>
<tr>
<td><a href="http://www.infoseek.com">http://www.infoseek.com</a></td>
<td>Web searches, Topic directory, current news, News groups, Company profiles including stock prices. No advanced search features</td>
</tr>
<tr>
<td><a href="http://www.lycos.com">http://www.lycos.com</a></td>
<td>Similar to the above and includes special advanced search features.</td>
</tr>
<tr>
<td><a href="http://www.yahoo.com">http://www.yahoo.com</a></td>
<td>The same in scope as those above but with a strong emphasis on the option to select by country</td>
</tr>
<tr>
<td><a href="http://www.google.com">http://www.google.com</a></td>
<td>A relatively new and interesting site</td>
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Do I Want More Information?

Globalhealth2000 * provides consumers with access to the world’s largest full text medical databases, including many in languages other than English. This website also provides access to MEDLINE, the database of the National Library of Medicine in the United States, also accessible directly at http://www.ncbi.nlm.gov Globalhealth2000 subscribes to HONcode principles of the Health on the Net Foundation and Globalhealth discloses that it receives funding from medical companies who are given banner placements. Unfortunately this category of information tends to present conflicting research results and the consumer needs to take the search one step further and search for evidence-based information such as that in the Cochrane Library (referred to earlier).

Do I Know How to Assess the Information’s Quality?

Consumers need to develop appraisal skills so they can start to assess information and website quality for themselves. As Motley points out in her AUSTRALIAN HEALTH CONSUMER article, our own gut instinct is fairly good when we reflect and consider how well the information retrieved met our specific needs. However, consumers are encouraged to start using assessment tools as these become available to ensure objectivity and informed decisions.

One such assessment tool is, The Discern Handbook: Quality Criteria For Consumer Health Information On Treatment Choices. This is available in full text from the King’s Fund website http://www.kingsfund.org.uk/ and consumers are encouraged to download the whole handbook and not rely on the following example questions taken from the handbook. Written from the consumer perspective, the handbook was designed to help consumers and information providers assess the quality of written information about treatment choices for a health problem. The handbook consists of 15 questions, which address certain features. These features need to be present if the publication is to be considered useful and appropriate for making decisions about treatment.

The 15 questions DISCERN recommend consumers asked?

1. Are the aims clear?
2. Does it achieve its aims?
3. Is it relevant?
4. Is it clear what sources of information were used to compile the publication?
5. Is it clear when the publication was produced?
6. Is it balanced and unbiased?
7. Does it provide details of additional sources of support and information?
8. Does it refer to areas of uncertainty?
9. Does it describe how each treatment works?
10. Does it describe the benefits of each treatment?
11. Does it describe the risks of each treatment?
12. Does it describe what would happen if no treatment is used?
13. Does it describe how the treatment choice affects overall quality of life?
14. Is it clear that there may be more than one possible treatment choice?
15. Does it provide support for shared decision-making?

According to Margaret Winker in her Journal Of American Medical Association article, concerns about the quality of health related websites tend to focus on the potential of the Internet to provide consumers with misleading or dangerous information. Lack of central
editorial control and rating instruments that are flawed, poorly developed and of questionable value are concerns raised by Jadad and Gagliardi, in their 1998, Journal Of American Medical Association article.

DISCERN has also developed criteria for assessing websites.

These criteria are:

- Is central editorial control visible?
- Are authorship credentials disclosed?
- Is site ownership disclosed?
- Are funding arrangements disclosed?
- Are sponsorship and commercial interests (if any) disclosed?
- Is the date of posting of information disclosed?
- Is the purpose of the site stated?

**My Own Internet Search**

My doctor said I would need to use medication indefinitely to ‘manage’ my asthma. I read two information sheets given to me during a consultation but felt I needed more information about possible adverse effects. I used the flow chart outlined in Figure 1 to aid my Internet search. Details of my Internet search are noted in Figure 2.
Step 1.  
Am I clear about what category of information I need?

I identified my initial information need as belonging to the categories:
1. Health Promotion - Information on establishing and maintaining healthy lifestyles
2. Prevention and Conditions - Basic information about the nature of a medical condition

Step 2.  
Do I know which search software to Use?

I chose the Yahoo search engine because it allows the search to be narrowed down to Australian websites and my preference is for Australian based information and services. I also used the health promotion websites e.g. healthinsite to find links to relevant sites.

Step 3.  
Do I want more information?

The basic information retrieved provided a general overview of asthma - signs and symptoms, causes, relievers, preventers and symptom controllers plus the six step asthma management plan. However, I wanted information concerning possible side affects so my information need had progressed to the category - Choices and Participation, therefore I returned to step one.

Step 1.  
Am I clear about what category of information I need?

This time I identified my information needs as being the Choice and Participation in Treatment Options category.

Step 2  
Do I know which search software to Use?

Websites that could provide information on research, evidence based research were selected including:
- http://www.jama - specialises in medical research including evidence based research
- http://www.looksmart.com - provides medication information

Step 3.  
Do I want more information?

I found information about side affects and contraindications of corticosteroids - medication in puffers used for treatment of asthma. The side affects were listed as including “thinning of the skin, easy bruising, cataract formation, glucose intolerance, alterations in sleep cycles, osteoporosis and immune suppression”. I was now in a position to discuss these side affects with my doctor.

Step 4.  
Do I know how to assess the information’s quality?

Satisfied I had enough information covering all my questions, I used DISCERN criteria to assess the quality of websites used and information received, confident I had a sound framework to use to appraise the information.
Conclusion

DISCERN tools have the potential to address many of the concerns commonly expressed by providers about consumers having access to misleading health information on the Internet. My concerns are with the number of websites duplicating the same incomplete information in an unlimited variety of formats making the task of finding relevant information more frustrating than it need be. There are two challenges ahead - providers of health information on the Internet need to coordinate their efforts - particularly when the information they are providing is on the same topic and location is not an issue. The second challenge is for consumers to explore and keep a record of the sites they find useful. The result will be confident and informed consumers armed with skills needed to appraise health information on the Internet.

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