

# Finding health information on the Internet: health consumers

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**The quality of health information on the Internet is extremely variable. This article highlights some of the problems consumers encounter when searching for health information and suggests ways in which these can be overcome.**

### INTRODUCTION

A recent article in *The Independent* newspaper (Dobson, 1999) discussed a new epidemic that is terrorizing today's health professional. Known as 'Internet Printout Syndrome' this condition usually manifests in the form of a 'thick wad of printouts, downloaded from the Internet' (Brown, 2000) that are presented during a consultation.

Patients and their carers are increasingly turning to the Internet for information. The reasons for this are many — to seek a second opinion, to be better informed, or to seek support from fellow patients — and as a consequence, the balance of power in the doctor-patient relationship is now changing. Information that was once the exclusive prerogative of the health professional is now available to anyone who can access the Internet.

The high level of interest in online health information can be shown in many ways. For example, a survey undertaken by Harris and Associates (2000) estimated that in the past 12 months some 60 million American citizens went online in search of health information. In the UK, figures from the NHS Direct Online service show that in the first 4 weeks of operation the site attracted over 7 million hits. Finally, figures from Alexa <http://www.alexa.com> indicate that the PubMed Medline service is one the top 400 most visited sites on the Internet.

The quality of health information on the Internet is, however, extremely variable. This article highlights some of the problems consumers encounter

when searching for health information, and some ways of overcoming these are suggested.

### HEALTH INFORMATION ON THE WEB: CURRENT PROBLEMS

Within the results page of a simple search on 'cancer' one can move almost seamlessly from authoritative sites like CancerNet <http://cancer.net.ncl.nth.ac.uk/> and OncoLink <http://www.oncolink.upenn.edu/> to highly dubious sites, such as Dr Clark's 'Cancer can now be cured' site <http://www.drclark.net/>. Here, for example, visitors are informed that:

**'...all cancers are alike. They are all caused by a parasite...and if you kill this parasite, the cancer stops immediately'.**

In the light of this statement one should not be surprised to learn that:

**'Electricity can now be used to kill bacteria, viruses and parasites in minutes, not days or weeks as antibiotics require. If you have been suffering from a chronic infection or have cancer, or AIDS, learn to build the electronic device that will stop it immediately [or buy one]. It is safe and without side-effects and does not interfere with any treatment you are now on.'**

Another page at this site [http://www.drclark.net/disease/zap\\_pix.htm](http://www.drclark.net/disease/zap_pix.htm) provides readers with an opportunity to buy the 'New Super Zapper DeLuxe' for \$149.99. Quite what this does is difficult to say, but what is certain is that it is not a cure for cancer.

Information bias is another problem health consumers need to be alert to. The official sounding 'National

Vaccine Information Center' <http://www.909shot.com/> is a national, non-profit educational organization founded by parents whose children were injured or died following vaccine reactions. Not surprisingly, therefore, the site presents a fairly one-sided and negative view of childhood vaccinations. On the home page, for example, one can read about a thriving 2-month-old baby who died after being given the diphtheria-pertussis-tetanus (DPT) vaccine, and of a 13-day-old baby who died following a hepatitis B injection. Although it is important that such concerns are brought to the attention of parents, equally there is a need to balance this information with the positive benefits of childhood immunisation.

Finally, most consumers have not had the benefit of many years of medical education. Consequently, even if the information retrieved is accurate and evidence based there are still potential problems. For example, most consumers are not in a position to know whether generic information found on the web would be suitable — it may contraindicate other medication currently being prescribed — or even whether the treatment suggested is available. Viagra (sildenafil) was licensed in the USA some 6 months before it was available in the UK.

In the light of these problems the solution may be to try and discourage patients from using the Internet for health information. I do not believe such a strategy is either sustainable or wise. Figures from the Office of National Statistics (ONS) indicate that 25% of UK households have Internet access (ONS, 2000). Research shows that providing consumers with information about treatment choices

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reduces anxiety (Fallowfield et al, 1990), promotes a more effective relationship with health professionals (Meredith et al, 1995), and can lead to improved health outcomes (Brody et al, 1989).

Consequently, a better strategy may be to help consumers use the Internet effectively. This can be achieved by:

- Directing consumers to high-quality gateway services
- Alerting consumers of the need to critically appraise the information
- Encouraging consumers to discuss the results of their research with health professionals.

### CONSUMER INFORMATION GATEWAYS

Over the past few years a number of consumer-focused health information gateways have been established. The purpose of these is to direct users to Internet resources that meet a defined quality criterion. Three of the most authoritative sites are discussed below.

#### Medlineplus

<http://www.nlm.nih.gov/medlineplus>

Developed by the National Library of Medicine, Medlineplus directs visitors to selected online publications, web sites, and self-help groups that produce reliable information for the public. On using the A-Z health topics list someone interested in, for example, osteoporosis is directed to publications authored by bodies such as the American Academy of Orthopaedic Surgeons, the National Osteoporosis Foundation and the National Institutes of Health. Within each disease topic resources are divided into more specific categories, thus enabling the user to focus on his/her area of interest. In the case of osteoporosis, subtopics available to the user include clinical trials, diagnosis, therapy, pictures, and statistics.

In addition, Medlineplus provides access to 'clickable' Medline searches. Thus, someone interested in finding out the latest research into the prevention of osteoporosis is presented with a single hypertext link. On hitting this, a predefined search — using all the appropriate medical subject headings (MeSH) headings and subheadings

along with Boolean operators and limits — is executed. By providing access to Medline in this way health consumers can identify current, peer-reviewed research without having to learn how to search and understand this large and complex database.

#### NHS Direct Online

<http://www.nhsdirect.nhs.uk>

NHS Direct Online is the UK equivalent to Medlineplus. Although this service is not as well developed as Medlineplus, it does provide a useful starting point for UK consumers. For example, the monthly-featured topics — screening is the current topic for analysis — bring together a range of high-quality Internet resources. In the article on screening, links are provided to online abstracts from the Cochrane Library, articles in journals such as *Bandolier* and *Effectiveness Matters*, as well as more patient-focused sites such as support groups and online audio clips.

The site also provides a Conditions and Treatment database that provides contact details for major national self-help groups and details of evaluated patient information leaflets and booklets on treatment choices. My only criticism of this database is that many of the recommended sources are printed leaflets which have to be requested by ordinary mail.

#### Patient.UK

<http://www.patient.co.uk>

Launched in April 1998 — some 18 months before NHS Direct Online went live — this site aims to provide a comprehensive listing of UK patient orientated web sites. Developed and run by two GPs from Newcastle, the site can be both searched and browsed. When browsing the user can select one of 28 broad subject categories — child health, diseases and illnesses — while the more focused user can use the cross-referenced alphabetical index.

Continuing with the osteoporosis example, patient.co.uk provides links to sources such as the UK National Osteoporosis Society, online fact sheets and articles published in the *British Medical Journal*.

### CRITICAL APPRAISAL

In addition to directing users to high-quality gateway sites, health professionals should also alert consumers of the need to critically appraise the information they find. In the main, resources found through the sites discussed above will be of high quality. However, there will be times when these services do not provide the answer to the question and a broader search, using general Internet search engines like Google and Northern Light is required.

As virtually anyone can publish on the web, it is important to critically appraise the information that is found. In particular, health consumers should be suspicious of 'miracle cures' and sites which offer no independent evidence to substantiate their claims. Based on the work by Silberg et al (1997), any medical web page that fails to comply with the minimum standards set out below should be rejected:

#### Authorship

The author(s) of a web page, along with their affiliations and credentials should be clearly stated.

#### Attribution

If a web site is citing research as evidence then the source of this data must be stated.

#### Disclosure

The owner of the web site should be prominently displayed, along with any sponsorship, or advertising deals which could constitute a conflict of interest.

#### Currency

Web pages should state when they were created, and last updated.

A number of online tools have been created to help develop critical appraisal skills, including Discern <http://www.discern.org.uk> and the Information Quality (IQ) Tool <http://hitiweb.mitrectek.org/iq/default.asp>.

Both of these services provide a list of questions and discussion points that consumers need to be aware of when evaluating a site's strengths and weaknesses.

## OPEN DISCUSSION

An article in the *Medical Journal of Australia*, on the changing role of the doctor in the Internet age, concluded that 'it is time to embrace the concept of the informed patient and use their web-surfing skills' (Pemberton and Goldblatt, 1998). Patients and their families often have more time to search the Internet than their GPs and can limit their search to just one clinical condition and as a consequence will come across information that the doctor is unaware of.

To help minimize the danger that scarce and expensive consultation time may be spent looking at potentially

worthless information, Pemberton recommends that professionals adopt more proactive strategies. Suggestions include asking patients to send the information they have found in advance of the consultation, and advocating that health professionals set up their own web pages which direct patients to high-quality, evidence-based information.

## CONCLUSION

The Internet offers opportunities and threats to today's information-seeking health consumer. Information on the web can be inaccurate, biased, and even harmful. On the other hand, used judiciously and with active support

from professionals, this new medium presents everyone with the opportunity to become active and informed partners in the health-care process. **HM**

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## KEY POINTS

- The quality of health information on the Internet is extremely variable.
- Patients are increasingly turning to the Internet to find health information.
- The doctor–patient relationship is changing as patients become better informed about health care.
- Health professionals need to develop strategies to help consumers use the Internet effectively.
- Evaluated gateway services are a recommended starting point for information-seeking consumers.
- Patients need to develop critical appraisal skills.