The role of quality tools in assessing reliability of the Internet for health information

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Abstract
The Internet has made it possible for patients and their families to access vast quantities of information that previously would have been difficult for anyone but a physician or librarian to obtain. Health information websites, however, are recognised to differ widely in quality and reliability of their content. This has led to the development of various codes of conduct or quality rating tools to assess the quality of health websites. However, the validity and reliability of these quality tools and their applicability to different health websites also varies. In principle, rating tools should be available to consumers, require a limited number of elements to be assessed, be assessable in all elements, be readable and be able to gauge the readability and consistency of information provided from a patient's view point. This article reviews the literature on the trends of the Internet use for health and analyses various codes of conduct/ethics or 'quality tools' available to monitor the quality of health websites from a patient perspective.

Keywords: *Quality tools, kite marks, health information, Internet and websites*

1. Introduction

The Internet has been used as a source of health information since the early 1990s [1] and is now an increasingly popular choice. In a report based on the findings of a daily tracking survey on an American's use of the Internet and data from telephone interviews conducted by Princeton Survey Research Associates International during August 2006, among a sample of 2928 adults it was noted that 80% of these had searched for online health information [2]. This interest is not confined to the US, two British surveys recently have also shown a gradual increase in public interest in the use of the Internet for health information. The Internet in Britain: The Oxford Internet Survey 2005 has shown that 37% of the study population used the Internet for health with 20% using it several times. This study, which is based on an interview survey of 2185 British residents (age > 14 years) has shown that Internet

penetration in Britain was, at that time, 65% and was growing with a 3% increase, reported between 2003 to 2005 [3]. A more recent study, carried out by the Welsh NHS surveyed 1002 people between March and May 2006 and reported that approximately four out of five respondents (84%) had access to a computer either at home, work or another location and a similar proportion (78%) had Internet access. Around two thirds (66%) of those with access to the Internet had used it to obtain some type of health information [4].

A large telephone study in the USA by Fox *et al.* explored the role of the Internet for health information in general public (total $n = 12,751$, Internet user $= 6413$, age > 18 years). Forty per cent of the regular Internet users reported that the advice they found on the web had improved the way they took care of themselves, 55% reported that access to the Internet improved the way they obtained medical and health information. Seventy per cent reported that the web information influenced their decision about treatment, 50% reported that this led them to ask a doctor new questions or get a second opinion and 28% reported that this affected their decision about whether or not to visit a doctor. The survey results were used to estimate the approximate number of Americans, in millions, who engage in Internet activities. This study suggested that 52 million adult Americans – 55% of the Internet-user population – would be likely to use Internet sources to seek health information (health seekers) and the majority of these would go online at least once a month for health information [5].

Because of the Internet, for the first time, consumers have equal access, with health care professionals, to the knowledge bases of medicine – and those 'connected' are making extensive use of this. For example, when free public access was opened, the number of Medline searches performed by directly accessing the database at the National Library of Medicine increased from 7 million in 1996 to 120 million in 1997. The new searches are attributed primarily to 'non-professionals' [6]. It has been argued that a driving force behind demand for online health information is the shortage of information easily obtained from traditional channels [7]. With the duration of an average consultation is still only 7 min in the UK (and 12 min in the USA), it is perhaps unsurprising that professionals routinely fail to address the information needs of consumers [8].

The need for information by consumers of health products has lead to a rise in the number of health websites. It is difficult to quantify this but a search on Google (www.google.com) of a medical term produces millions of web links and over a billion links for 'health'. As well as providing information, the Internet, being available at all times, also supports conferences [9] and chat rooms [10] and provides the opportunity for long-term ongoing support among patients and between patients and providers. In addition, the Internet can be used to monitor patient status, collect data and provide tailored feedback and self-management counselling [11,12] and offers the advantages of interactivity, information tailoring and anonymity. This provides the potential for opportunities for patients to become well informed and to take an active part in their own treatment process. However, such use of the Internet also raises many issues concerning the quality [13,14] of the information available and the relationship between patients and health care providers [15–17].

Quality of information is a known issue for Internet health solutions. The Health on the Net Foundation (HON) surveyed 2621 volunteer respondents between May and June 2002. The respondents (patients and health professionals) were mainly from North America (43.5%) and Europe (29%), and both groups of respondents, patients and health professionals agreed that 'accuracy of information' was the most important issue facing the medical Internet. The next item of concern for patients was 'trustworthiness' and for professionals, 'finding information/navigation' and 'availability of information' [18]. It is important to differentiate between the needs of patients and professionals. For patients, convenience and cost savings are primary reasons to use the Internet, for health care providers, the primary aim is to gather

medical information [19]. For both of these groups, however, as the quality of medical information available on the Internet is variable and the quantity is constantly increasing and changing [20–22], there is a need for rigorous assessment of quality and efficacy of health websites for different fields of medicine. Quality is defined as 'the totality of characteristics of an entity that bear on its ability to satisfy stated and implied needs' [23]. For quality to be evaluated, these needs have to be defined and translated into a set of quantitatively or qualitatively stated requirements for the characteristics of an entity that reflect the stated and implied needs [24]. Although the Internet's power to positively affect care management seems intuitive, its value for improving health outcomes must be examined and documented to provide a basis for further advancement in different fields of medicine. This article reviews various codes of conduct/ethics or 'quality tools' available to monitor the quality of health websites from a patient view point.

2. Quality of e-health online resources

Health information on the Internet varies significantly and web users have been warned regarding the possibility of incomplete, misleading or inaccurate medical information available on the web [24,25]. Health websites giving information on a variety of topics like breast cancer [26], gynaecological problems [27], thyroid cancer [28,29], colorectal diseases, back pain [30], anaesthesia [31], bone tumours [32] and rheumatoid arthritis [33] have been evaluated in various studies and described to have inconsistent information in terms of quality of contents and reliability [27,34,35].

2.1. Health risks of the Internet

Unfortunately, access to information without structure, education, or guidance is not always in the best interest of the patients or their physicians. There is often a chance of misleading and incorrect information on certain websites [36]. For example, a study by Gordon *et al.* [37] evaluated the Internet as a source of information for the layperson on the topic of breast augmentation. The study showed that 83% of the sites were biased towards a particular surgical technique and only about 15% of the sites were acceptable to be recommended to patients. It is obvious that understanding the validity and applicability of medical information available can be difficult for those without a medical degree or extended training in the medical field. Incorrect or misleading information may lead to potentially dangerous health behaviour, e.g. patients reading information intended for health professionals may misunderstand information or may get wrong expectations regarding treatment options [36,37].

Because the medical information available on the web varies in quality, and because the medical professions are unfamiliar with the potential resources of the Internet, a vast majority of physicians have avoided encouraging patients to seek medical information through this venue [25–34,38,39]. Meric *et al.* [26] evaluated 184 breast cancer websites for quality of contents according to JAMA benchmark and found significant variation in accuracy [25]. Of the 184 sites, 12 (7%) contained inaccurate medical statements. Commercial sites contained inaccurate statements more often than did the sites of professional groups or of organisations – 11/84 (13%) *vs.* 1/36 (3%) *vs.* 0/64 ($p = 0.004$). Three (16%) of 19 commercial sites that displayed the Health on the Net seal contained inaccurate statements. Higher quality sites (at least three JAMA benchmarks) were less likely to contain inaccurate information than lower quality sites (fewer than three JAMA benchmarks) – 1/64 (2%) *vs.* 11/120 (10%) ($p = 0.047$). None of the 16 sites that met all four JAMA benchmarks contained inaccurate information. A limitation of the study is that a single reviewer assessed the accuracy. Therefore accuracy is

inherently subjective, so the results should be confirmed by studies using a panel of experts. However, it highlighted an important point that the quality of the websites can vary even if they possess a benchmark, e.g. HON and JAMA in this series.

Other patient behaviour that worries doctors is when consumers turn to the Internet for their prescription drugs and for online consultations. It has been shown that although the Internet may expand public access to pharmaceuticals, the actual cost of drugs purchased online may be higher and the potential for serious abuse exists, in that patients can obtain medications relatively easily, even on those sites with high standards, by providing false or incorrect information [40]. It is interesting to remark, that in the UK, online consultations are legal primarily because of a loophole in the Medicines Act of 1968. The act states that many drugs can be dispensed only after a patient has had a consultation with a doctor, but it does not lay down that this should be face-to-face [41]. The General Medical Council has taken action against four doctors since 2002 for prescribing drugs over the Internet without a proper consultation [41]. Law enforcement officials, in the US, also report an increase in drug trafficking on the Internet, as young people use online chat rooms to negotiate sales as both buyers and sellers [42].

2.2. Seeking health information online

For those seeking easy ways to identify high-quality, reliable information, some websites and organisations have provided rating systems to score the quality of information on the Internet. However, these systems often do not provide the criteria used to assess quality, nor do they provide the reliability and validity of their measures [24]. Ultimately, assessing the quality of content depends on the same factors that readers of print publications depend on; authorship of the content, attribution to the sources of content, disclosure of funding and competing interests, and timeliness of the information presented [25]. The enthusiasm for readily available medical information was witnessed at the launch of the National Library of Medicine's popular MEDLINE service. The organisers of this website were 'amazed' that about one third of the searches were being conducted by general public [43].

In the past, outside of layman press articles, individual contact with a physician was the only way a patient was educated regarding medical information. This was followed by books like 'Family Doctor' and health programmes on various television channels. Now the Internet makes access to medical information universally available with websites like NHS Direct (www.nhsdirect.nhs.uk). Even the Family Doctor is available online (http://familydoctor.org) and the public can watch television health shows on the television channel websites such as http://www.bbc.co.uk/health/.

3. Development and need of code of ethics/kite marks

To minimise the potential risks of the Internet, codes of ethics or quality tools for health websites have been developed with a common aim to design and implement a valid method for evaluating the quality of Internet health sites, which could provide lay people with a tool to locate useful content more easily and have confidence that the information is accurate and complete [44]. The use of codes of ethics has also been adopted by the business and marketing industry [45]. Similarly many different organisations are using varied approaches to try to determine ethical guidelines for health information on the Internet in order to provide precise, up to date and consistent information [46]. If a third party organisation develops a code of conduct and allows those who undertake to abide by the terms of the code

to display a label, seal or logo which certifies compliance with the code, then these logos are called kite marks [47].

3.1. Ethics/quality standards for online services

Several organisations are trying to develop a standard code of ethics for the Internet health care industry. Specifically, Hi-Ethics (Healthcare Internet Ethics), Health on the Net Foundation and the Internet Healthcare Coalition's E-Health Ethics Initiative have combined to develop an E-Health Code of Ethics. Some professional medical societies also are beginning to develop their own code of ethics, and to screen health information websites as a service for their members. As an example, the Journal of the American Medical Association (JAMA) has developed an extensive code of ethics, which is published on the website of the American Medical Association (AMA) [48]. Some of the codes of ethics described in the current literature [46] are summarised in Table I and the approaches which have been used to develop the codes are given in Figure 1 and discussed below.

3.1.1. Self-regulation or self-governance. The predominant Internet industry and public policy approach to addressing ethical concerns is to encourage voluntary codes of conduct and industry self-regulation or self-governance [65]. The Health on the Net Foundation (HON) developed one of the first codes of conduct set of principles, the Net Code of Conduct [49]. The British Healthcare Internet Association has published Quality Standards for Medical Publishing on the web and an Internet Bill of Rights for Access to Health Information on the Net [50] and Editors of the Journal of the American Medical Association published guidelines for 'assessing, controlling and assuring the quality of medical information on the Internet' [25,66].

Lundberg expanded the definition of Medical Internet Ethics to include medical ethics, journalism ethics, business ethics and the ethics of medical editing [66]. In addition to

Table I. Examples of code of conduct systems for health websites.

Self regulation or self governance based code of ethics
    Health on the Net Foundation, HON (hon.ch) [49]
    The British Healthcare Internet Association (bhia.org) [50]
    American Medical Association (ama-assn.org) [48]
    American Health Information Management Association (ahima.org) [51]
    International Committee of Medical Journal Editors (icmje.org) [52]
Rating tools
    Information Quality (IQ) tool (Hitiweb.mitretek.org) [53]
    DISCERN (discern.org.uk) [54]
    Health Education Authority and the Centre for Health Information Quality (quick.org.uk) [55]
Third-party reviewers
    New York Online access to Health, NOAH (noah-health.org) [56]
    Medweb, (medweb.emory.edu) [57]
    Netwellness (netwellness.org) [58]
    InteliHealth (intelihealth.com) [59]
    Mayoclinic.com (mayohealth.org) [60]
    Medical Matrix (medmatrix.org) [61]
'Accreditation' system
    American Accreditation HealthCare Commission (urac.org) [62,63]
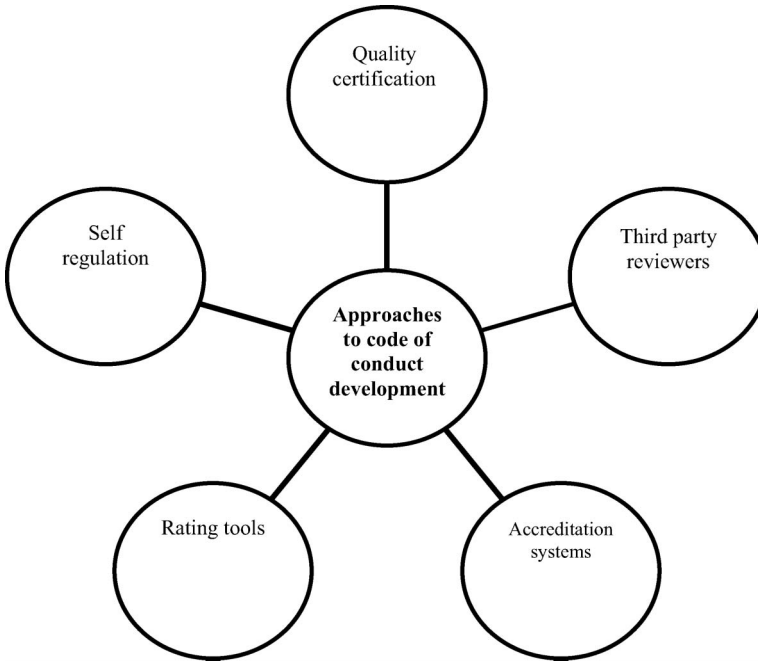Certification system
    MedCERTAIN [64]

Figure 1. Different approaches currently in use to develop code of ethics.

medicine, if one expands the definition and includes business and journalism ethics, other professional organisations and their codes include: the Society of Professional Journalist's Code of Ethics [67] the American Health Information Management Association's (AHIMA) recommendations to ensure privacy and quality of personal health information on the Internet [51] and the International Committee of Medical Journal Editor's (ICMJE) policy statement about publishing on the web [52]. The major limitation to this approach is that self-regulation does not deter the unscrupulous, those who mostly need to have their ethical standards raised.

3.1.2. Rating tools. A second approach relies upon healthcare consumers evaluating websites for quality using a checklist or rating tool. Different rating tools are available to consumers – if they know where to find them. The Health Summit Working Group of the Health Information Technology Institute of Mitretek Systems developed a web-based interactive Information Quality (IQ) tool for use in assessing the quality of health information on the Internet [68]. DISCERN is a brief online questionnaire, developed by the University of Oxford's Division of Public Health and Primary Health Care, at the Institute of Health Sciences. This questionnaire provides Internet users with a valid and reliable way of assessing the quality of consumer health information [69]. The Quick website tool, developed by the Health Education Authority and the Centre for Health Information Quality, is designed to be used as a teaching aid for children in an educational setting [70]. Allowing users the chance to rate their own experiences is good but the downside of most checklist approaches is that they require the consumer to be motivated enough to seek out, understand, and then use the rating tools.

3.1.3. Third-party reviewers. A third approach utilises third-party reviewers – physicians, academics, nurses, librarians and other experts – to evaluate health information and write

reviews or create useful lists of sites, so that users, patient or physician, can determine the quality of information at these sites [46]. Review sites can be libraries such as New York Online access to Health (NOAH) [71] or Medweb [72]; university-based or university-sponsored such as Netwellness [58], InteliHealth [73] or Mayoclinic [61] or non-profit-based such as Medical Matrix [74]. The reviewer's approach can be very labour intensive and, dependent on the frequency that reviewed materials are updated. It is similar to 'novice review' which means taking help from online consumer reviews about different products such as electronic equipment [75].

3.1.4. 'Accreditation' systems. Fee-based rating or 'accreditation' systems for medical and health websites are also being established. In May 2001, URAC ('American Accreditation HealthCare Commission', see www.urac.org, to explain the discrepancy in their names [76]) and Hi-Ethics [77] announced that they would be collaborating on the URAC Health website Accreditation programme as a way for health websites to demonstrate their compliance with ethical standards. Currently 300 websites are URAC-accredited. One concern with implementing fee-based accreditation systems is that this system favours the larger, well-funded organisations. URAC's proposed fee structure may exceed the yearly operating budget for many of the medical and health information websites. There is concern that the presence of seals of approval and certifications may provide a false sense of security and mislead consumers unless there is a system of enforcement and rigorous verification [65].

3.1.5. Certification and rating of trustworthy health information on the Internet. A next-generation approach is being developed by MedCERTAIN called 'MedPICS Certification and Rating of Trustworthy Health Information on the Net' [64]. This project is developing a self-rating and third-party rating system enabling individuals, organisations, associations, societies and others to filter health information and identify and select high quality information. The MedCERTAIN consortium will also establish an international trust mark for health information by creating different levels of certification for those who publish health information on the Internet. Websites in need of the MedCERTAIN certification will have to commit themselves to the e-Health Code of Ethics [64].

Online ethics of commercial medical websites and the ability of the online healthcare industry to effectively self-regulate, grabbed the limelight in the letter part of 1999 after several prominent medical and health websites in the US showed questionable ethical behaviour. Among the complaints were that the distinction between objective information and advertising or promotional content was hazy and that business ties were not properly disclosed [78]. Other questionable practices included non-disclosure of business partnerships, cookies tracking unsuspecting visitors and blatant conflicts of interest, with officers profiting from insider stock trading [79–81]. Since then, efforts to create codes of ethics for web-based medical and healthcare activities have intensified.

One of the first codes of conduct for health and medical websites was developed by the HON in 1996 [49]. The following year the American Psychological Association's Ethics Committee created guidelines for their members for dealing with services provided by telephone, teleconferencing and the Internet. In September 1999, Medscape published their advertising and sponsorship policy, 'The Ethics of the Medical Internet' [25]. During 2000, the AMA published guidelines for their medical and health information sites on the Internet to follow [82], the Internet Healthcare Coalition's (IHC) e-Health Ethics Initiative published an International Code of Ethics [83], the MedCERTAIN consortium published a statement of purpose and the Consensus Recommendations on Trustmarks [84] and Health Internet Ethics (Hi-Ethics) published Ethical Principles for the Health Internet [85]. Many of the

most-trafficked health websites (America Online, Discoveryhealth.com, drkoop.com, Healtheon/webMD, InteliHealth, Mediconsult/Physician's Online, and Medscape) agreed to be compliant with the Hi-ethics principles [86].

3.2. Code of conducts and quality instruments, is there a single solution?

Baur and Deering of the US Department of Health and Human Services tried to make some sense of the different frameworks. They reviewed four main private-sector proposals – HON, AMA, IHC and Hi-ethics – and compiled a side-by-side comparison of the key elements for improving the quality of health websites. They found that the various codes may have different audiences and different purposes, with different motivations for developing a framework, yet all are being promoted to the general public as ways of improving quality [65]. They concluded that the majority of the codes of conduct and quality tools were designed to be used for all types of health websites in general and have potential limitations.

It is also important to emphasise that quality seals in the form of kite marks may give a false sense of security. In a study on the quality evaluation of kidney transplant websites, we found that the websites belonging to academic institutions were the best in providing information for patients and there was no difference in the quality of information on the kitemarked websites when compared with low quality commercial or individual websites [87]. In the presence of so many quality/rating and ethics tools, there seem to be no single universally acceptable framework to assess the quality of all types of health websites with one instrument. One possible solution worth trying would be the development of speciality based quality tools.

4. Selecting health websites

Common sources of health information on the Internet include university and hospital websites, large commercial corporate health websites (webmd.com and Mayohealth.com) and commercial supplier websites like pharmaceutical companies and medical society websites (e.g. British Transplantation Society (BTS) website, http://www.bts.org.uk/) (Figure 2).

Three guidelines are commonly used to evaluate websites, the AMA, the Health on the Net Foundation (HON) and Health Internet Ethics (Hi-Ethics) guidelines [88]. According to the guidelines, in general a useful website for patients with a specific disease is one that provides in-depth information on a wide array of specific health issues. It should be financially nonbiased, and it should meet high ethical standards developed for information transfer which include [88]:

- Provide health information that is secure and trustworthy.
- Clearly identify online advertising and disclose sponsorships or other financial relations that significantly affect the site's content or services.
- Keep personal information private and secure and employ special precautions for any personal health information.
- Empower consumers to distinguish online health services that follow their principles from those that do not.

For physicians to choose the website most useful to their patients without needing regularly to scan more than the 25,000 available health websites available, they may rely on web review services that frequently audit website quality and ethics. One service that does just this is
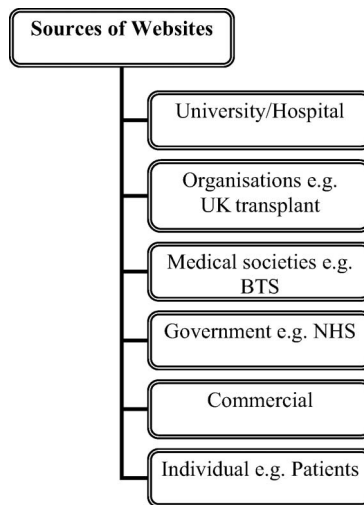
Figure 2. A classification of different sources of health websites. BTS, British transplantation society.

provided by the National Institutes of Health (medlineplus.gov). This service provides free access to information collected from its own sources, other government organisations, professional societies, universities and other high-quality sources. This service ensures that the sites adhere to ethical standards and are of high quality. MEDLINEplus is a useful resource for guiding physicians to health websites that focus on issues pertinent to their needs. Similarly, The US Department of Health and Human Services provides an Internet service (healthfinder.gov) that screens health care sites and links to those that meet its ethical and quality guidelines.

Well-educated patients, who can share in their decision-making process, are much better able to access the health care system. Shared decision making has been known as the 'missing piece' in some of the biggest health care systems [89]. Credible disease-specific websites will better educate patients, and assist them in more efficiently directing their care to generalists, specialists, or self-care [90].

5. Conclusion

In the modern world, where e-technology becomes common place, patients deserve e-services which are informative, trustworthy and useful. The challenge for clinicians is to make this happen. Medical websites and the Internet provide a new foundation for self-health education and can be used for reporting, monitoring and feedback of patient self-care assignments. The literature has shown that there is a great variety in the quality of information available on the Internet on different health websites and also in the quality criteria and the code of ethics governing them. None of the code of ethics has been proven universally acceptable to evaluate the quality of information of different health websites. Although the Internet has brought the possibility of a more equitable distribution of knowledge, the liberty and variety of possible choices bring risks and doubts. When seeking information on the Internet, the doctor and, indeed, the patient must rely on quality criteria established by representative authorities. More work is needed to develop and establish reliable indicators of quality health websites.

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