Chapter 1.14

Quality of Health Information on the Internet

Kleopatra Alamantariotou
City University London, UK

ABSTRACT

Recent statistics show that the World Wide Web has now grown to over 100 million sites: a phenomenal expansion in only 15 years (Mulligan 2007). It has been estimated that there are 100,000 sites offering health related information (Wilson 2002). As the amount of health information increases, the public find it increasingly difficult to decide what to accept and what to reject (Burgess 2007). Searching for information on the internet is both deceptively easy and the same time frustratingly difficult (Kiley 2002). The challenge for consumers is to find high quality, relevant information as quickly as possible. There has been ongoing debate about the quality of information aimed at patients and the general public and opinions differ on how it can be improved (Stepperd 1999). The purpose of this chapter is to provide a brief overview of the different perspectives on information quality and to review the main criteria for assessing the quality of health information on the internet. Pointers are provided to enable both clinicians and patients find high quality information sources. An understanding of these issues should help health professionals and patients to make effective use of the internet.

INTRODUCTION

Health information includes information for staying healthy, preventing and managing disease, and making other decisions related to health and health care. It includes information for making decisions about health products and health services. It may be in the form of data, text, audio, and/or video. (Dzenowagis 2001)

The Internet provides a powerful tool for patients seeking medical information. It offers consumers access to a wealth of health and medical information that can enable them to take responsibility for their own health (Linkous 1999). Information is the communication or reception of knowledge. Such communication occurs in great part through the recording of knowledge (Taylor 2004). Some commentators predict that in the near future the Internet will be an important vehicle for deliver-
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ing information and medical care. Tom Ferguson coined the term “e Patients” to define those people who were empowered to find medical answers for themselves, rather than rely on any single individual’s opinion or interpretation. Virtual children’s Hospital based the Internet’s first medical Web site since 1993 (Risk 2003).

The number of health related Web sites is rising with more than 70,000 sites available to patients in 2000. A 2006 survey of 5,007 U.S. adults found that 84% of consumers claimed to have researched a health-related topic online in the past 12 months. (Fox 2006). Another survey reported that eighty percent of American Internet users (some 113 million adults) have searched for information on at least one of seventeen health topics. (Fox 2006). 75% of all adults on line (47% of all adults) use the Internet to look for health information. This amounts to 98 million adults nationwide. (David 2003). On average those who look for health information online do so on average 3.3 times every month (Fox 2006).

Faced with this explosion of online information the main challenge facing today’s information consumer is how to find high quality information that meets their personal needs, within an acceptable time frame. But whilst everyone agrees that information quality is an important consideration, the concept of quality is problematic since in medicine there are often gray areas where the evidence-base is poor, making it difficult to determine a gold standard (Lewis 2005). Quality is an inherently subjective assessment, which depends on the type of the information needed, the type of the information searched for, and the particular qualities of the consumer (Wilson 2002). Experts believe that formal methods are needed to describe and assess information quality. Naumann maintains that “quality is the main discriminator of data and data sources on the Web” (Naumann 2001).

The paradox of quality as Robert Pirsing notes is the fact that “even though quality cannot be defined, you know what quality is” (Pirsing 1974). Although the typical consumer may be able to produce and define what quality means to them, each individual’s perception of the quality of health information will vary depending upon their current circumstances and quality requirements (Burgess 2007).

A recurrent concern about online health information is that anyone is free to publish. Websites are set up by individuals, patient, charities, activist groups, commercial bodies either selling a product, as well as by health care professionals. The overwhelming majority of these resources are informal, quite often with no clinical input (Potts 2006).

RISKS POSED BY POOR QUALITY INFORMATION

It has never been easier for members of the public to access health information. In the twenty-first century it is taken for granted that patients may browse the Internet for the information about their condition, contact other patients by e-mail, send e-mails to their doctor or use touch screen kiosks in order to get health information (Jones et al 2005). But many believe there is a downside to this development. They fear that while the quantity of information has expanded exponentially, the same is not true for its quality. There is a concern in many professional groups about the potential harm associated with the use of poor quality health information. The quality of health information is of a particular concern because misinformation could be a matter of life and death (McClung 1998, Crocco 2002).

Harm in this context may be defined as adverse events or bad outcomes, either physical or emotional or financial, that occur from acting on materials or information and medication obtained from a Web site. On the other hand Crocco and colleagues found only a few cases in the literature of harm associated with poor quality health information on the Internet. In particular the authors report on a systematic review of peer-reviewed